



Facing the Future



Living with confidence

*after treatment for head
and neck cancer*

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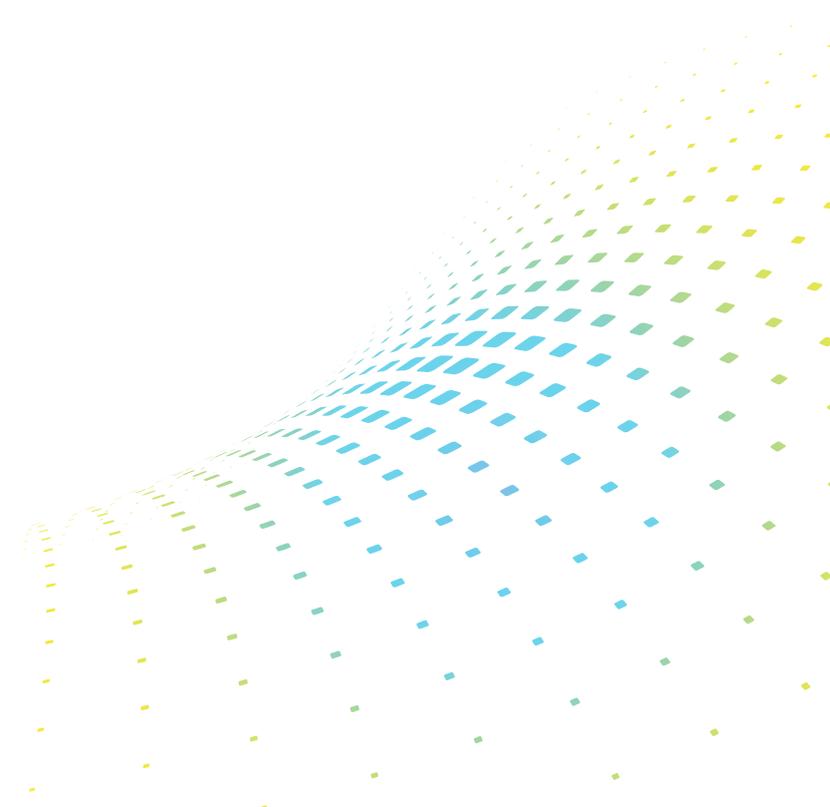


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Introduction

Finishing treatment is something you have probably thought about and looked forward to, and now here you are – congratulations! People who have experienced treatment for head and neck cancer often say that when they look back, finishing treatment was in fact the beginning of getting on with life. But getting on with life can sometimes be challenging, especially if you don't feel that you have much guidance – you might find yourself wondering what you can do to stay well, how to improve your energy levels, or what to do to get on top of side-effects of treatment.

This resource package has been developed to fill in these gaps. It aims to help you by providing information on what to expect now that you have finished treatment, and to give you some tools for being able to get on with life. The package was developed by health care professionals working in the cancer care team at the Royal Brisbane and Women's Hospital, using the best possible scientific evidence. Patients who have previously completed treatment for head and neck cancer have also contributed to this booklet. Their thoughts have been written in speech bubbles throughout the booklet.

Every person who has been treated for cancer is different, so not all of the topics included in this resource may be relevant for you. The best way to use the resource package is to read the sections that are important for you, and use the information you find most helpful. Remember that sometimes things change and different sections may become more or less useful over time. We have included thoughts from patients throughout the package who have finished treatment a while ago. We hope that this information will help you to feel more confident about getting on with life!



Moving Forward

Following completion of treatment for head and neck cancer most people think that they should *'just get on with it'* and have an expectation that life will return to normal. We know from our patients that days, hours and even minutes are sometimes counted off until the exact moment that treatment ends. The completion date becomes the goal, and treatment is the challenge to get through.

But once treatment is finished, you quickly realise that there are many more challenges – though completely different ones – ahead. When feeling so different from the way you felt before treatment, there is the huge challenge of returning to previous roles and relationships, work, family and social environments. It can be frustrating and difficult when the people around you don't fully understand how different and complex things can be for you now, and sometimes advice to *'move forward'* or *'put it behind you'* however well-meaning can add to the pressure, leading to the feeling that other people *'just don't get it'*.

This section of the resource suite talks about the emotional aspects of the experience and gives practical tips for some things that might be helpful. The first part is really about thinking about how the diagnosis and treatment have affected you, and the second part is the more practical things you might try. Everyone is different and not all sections will apply to you, so focus on the areas which are relevant to you.

How has this affected me?

1. The Diagnosis:

The diagnosis of any serious illness is a personal challenge. But we know that people who have been treated for head and neck cancer face a special set of issues, some of which are described below:

- Surgical treatments can result in marked physical changes, leading to self-consciousness socially. Changes in skin colour and texture after radiotherapy and reduced neck movement can also contribute to anxiety about resuming former social roles – such 'simple' things as driving can be a real problem. Coping with questions about what has happened or being aware that people are looking at you can be frustrating and painful reminders of the cancer
- Treatment is often with a combination of chemotherapy and radiotherapy leading to significant symptoms and often marked weight loss. In turn the weight loss reduces stamina and is associated with poor energy affecting mood and confidence. It probably doesn't help your ability to concentrate if you have lost a good deal of weight and you feel physically exhausted
- Dental extraction is a common part of treatment. Although necessary, a lot of people find it hard to adjust, finding that their bite feels very different, that their ability to chew and swallow is affected. Some people feel that their speech is different too

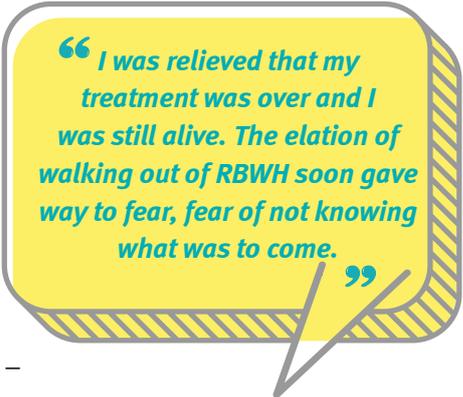
“Live one day at a time and do the best to not worry about the future.”

- Changes in taste and absent or reduced saliva make eating difficult, and sometimes anxiety about choking can reach the point where it severely affects quality of life. Feeling that you might choke is very scary, but sometimes people around you downplay this as they don't realise the fear it can cause
- Social interactions are often centred around sharing food and drinks with our friends and family. It can be tricky if the types of food available are not suitable or will cause you difficulty or take you a long time to eat. For some people this can lead to avoidance of social situations, which can lead to isolation and loneliness
- We don't fully understand why some people get head and neck cancer and others don't. Smoking and alcohol use are risk factors, but people who have never smoked or consumed alcohol can get head and neck cancer. Most people affected by cancer wonder why it happened and if they could have done anything to prevent it. Guilty feelings about having smoked or previously drinking high amounts of alcohol can play on people's minds and can be hard to talk about.

2. Coping with Treatment:

A lot of people find that coping with treatment is a bit of a blur. They know that they have to get through it and they struggle along the best they can. Having admissions for management of pain is not uncommon, and this means disruption of any routine you had managed to establish at home, and treatment with medications which bring their own side-effects. Constipation is a common side-effect of morphine – it seems such a minor problem until you have it yourself!

Some people can struggle to meet their nutritional needs due to pain from tumour site or the side effects of treatment impacting on eating and drinking. Some patients may have required tube feeding (nasogastric or gastrostomy tube) to help maintain nutrition intake during and even after the end of treatment. These patients will require ongoing input from Speech Pathology and Dietetics to transition through this period from tube feeding back to eating and drinking again.



“ I was relieved that my treatment was over and I was still alive. The elation of walking out of RBWH soon gave way to fear, fear of not knowing what was to come. ”



“ Just get through today. Let tomorrow look after tomorrow. ”

3. Completion of Active Treatment:

Most people look forward to finishing treatment. Especially if you have had to travel away from home for treatment it is a wonderful feeling to be back in your own home, to sleep in your own bed, and begin to resume 'normal' life again. But it often comes as a shock to realise that many things don't feel normal. A lot of people find it more complicated than they had anticipated. These are just some of the issues you may have to face:

- What to say to friends or family?
- Feelings of 'survivor guilt' and distress caused by thoughts about getting through treatment when others have not
- Decisions about returning to work
- Missing the contact with the hospital. OK, the treatment was ghastly, but at least you felt you were being looked after. What about now? Who is checking on you?
- Worry about whether the treatment has worked. What if the cancer comes back? Is there anything I can do to prevent the cancer coming back? We know that worry about cancer coming back is common and working out how to 'survive and thrive' despite this concern can take some time.

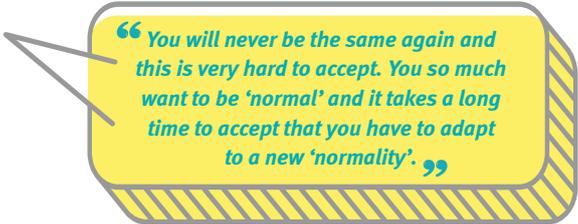
Practical issues and possible ways of adapting

1. Social Relationships:

Going back into social situations can be very confronting, especially if you feel that the surgery has altered your appearance. Changes in appearance can range from major changes to the appearance of your face, to redness of the skin, puffiness and some difficulty with speech, or a lop-sided smile. Often people don't know what to say – they are may be concerned about upsetting or offending you. If they pretend nothing has happened, it can be very distressing (*"After what I've been through and they just acted as though it was nothing"*).

Think about how you could handle this. Becoming angry and resentful will only hurt you. Maybe give people the benefit of the doubt – that their avoidance is not lack of concern but lack of knowledge about how to respond, or even the desire to 'protect' you from distress. Some people have found the following strategies helpful:

- Think about and prepare for a situation where you are likely to meet new people or see those you haven't seen since before your treatment
- Decide how much you want to discuss with people. The choice is yours, and of course this can change over time. What you want to discuss now may be quite different from what you discuss in two years' time
- Take the initiative about discussing the cancer – name the "elephant in the room".



“You will never be the same again and this is very hard to accept. You so much want to be ‘normal’ and it takes a long time to accept that you have to adapt to a new ‘normality’.”

Some suggestions include: *“Hi Tom, I guess you’ve heard about my run-in with the plastic surgeon. It’s sure been a tough ride”* or similar. This then ‘sets the tone’ for Tom about how you want to handle it

- Decide if you want to talk more about it or not. This can vary depending on how you feel and who the person is. If people ask questions or try to talk about it and you don’t want to go there, often a humorous comment allows you to take control and them to back off without anyone being too upset: *“Oh, Keith, you know I’ve decided I’m having a ‘cancer-free’ night tonight, but thanks for asking. Now tell me about that fishing trip you went on.”*

✓ *You choose what to say to other people and when*

✓ *You can change your mind over time*

✓ *Listen to what your mind and body tell you about what feels right*

2. Eating in Social Situations:

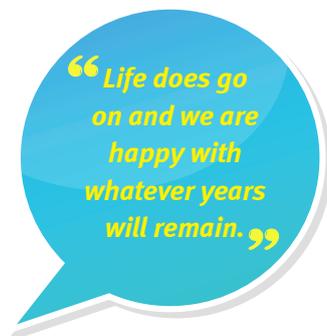
Some people may not completely understand the difficulties you may experience with eating and drinking. If you are worried about eating and drinking in social situations, the following may help:

- If you feel confident, openly talk to your family and friends about what you can and cannot eat and drink
- Consider taking suitable foods you can manage with you, so you don’t feel left out
- If you are going to a café or restaurant, it can be worthwhile checking their menu in advance. Often you can find this on the internet
- A lot of restaurants are very happy to cater for food needs if they have advance notice.

✓ *Planning helps*

✓ *Don’t panic about the odd difficult experience*

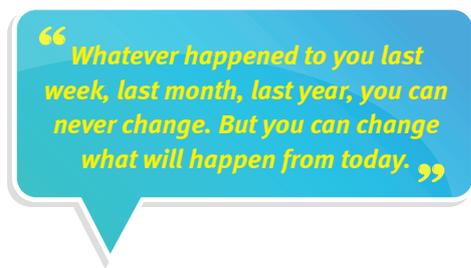
✓ *Be as accepting of yourself as you would be of other people*



“Life does go on and we are happy with whatever years will remain.”

3. Everyone Says I Have to be Positive:

A natural response to being diagnosed with any serious illness is to try to find a way to work out why it happened, and to control it. Cancer is of course no exception. One of the things people commonly wonder about is whether stress might have caused their cancer, and a large proportion of people believe that stress has brought on their cancer. You might be surprised to learn that scientific research doesn’t back up this view. There is no consistent scientific evidence that stress plays a significant part in the development of cancer, or the risk of it recurring. If stress plays any role it is clearly a very small one.



“Whatever happened to you last week, last month, last year, you can never change. But you can change what will happen from today.”

So, what about the people who urge you to be positive? Or the people who say how wonderful you look when you feel absolutely dreadful? They may not have access to evidence and results of research. It might also be that they are scared of facing up to how difficult the diagnosis and treatment has been. If they urge you to be positive, and say you look good, it can be a way for them to avoid thinking about what you have gone through – a way of protecting themselves from having to face up to the fact that bad things can happen for no apparent reason and that no-one (themselves included!) is ‘bullet-proof’:

- You do not have to make affirmations (like, “*I am strong, I will survive this cancer*”), unless this is what you want to do, and you find it helpful
- Family life is often stressful. That’s normal. Life is stressful. Think about stress as maybe even being helpful- for example if you didn’t have pressure about a deadline would you get your tax done on time, would you get to appointments on time, would you pay the bills etc?
- If you find yourself worrying about how you are coping or are troubled by ongoing side-effects of treatment you need to talk with your doctor about possible treatments and what you can do to cope.

✓ *Cancer does not come back because you have not been positive*

4. What Can I Do to Help Myself Feel OK?

Despite the urging of others to be positive, the evidence doesn’t support that this will necessarily make things easier for you and trying to be positive can in fact be stressful. Some useful strategies which have been shown to help many people include:

- Having realistic expectations of the rate of progress. Expecting to ‘get back to normal’ can really set you up to feel frustrated and angry that you haven’t been able to achieve what you want. Instead taking things steadily is useful. Being prepared to think about the ‘bigger picture’ over time rather than having to do everything at once and learning to pace yourself are also likely to be helpful
- Accepting that this is the ‘new normal’ rather than fighting the changes. This is especially the case in terms of fatigue and other side-effects. That doesn’t mean that you accept that things will never improve – but it does mean that you accept that things take time, and that setting smaller achievable goals is more helpful than very optimistic expectations which can lead to disappointment if you can’t achieve them
- Taking an active approach to problems is generally helpful. Most people find that information is helpful. Facing up to problems even if they are challenging allows you the opportunity to think through how you could tackle things, perhaps by breaking down issues into smaller chunks, and thinking about setting priorities. No military force would try to fight on multiple fronts – you have to think strategically about what is most valuable to you and choose your ‘plan of attack’!



- However, tempting it is to avoid thinking about problems, research shows that usually this leads eventually to more distress and tension, especially in relationships. More open communication is the way to go!
- Keeping contact with people who support and affirm you makes a huge difference. For many people having access to others who have ‘been there and done that’ gives a sense of optimism and confidence that things will improve over time. But don’t feel guilty if you don’t want to attend a support group – the important thing is to work out what suits you
- A lot of people find that relaxation or meditation can help them to feel calmer and more confident. These techniques suit some people better than others so don’t feel concerned if they don’t work for you. Despite what you might hear, these techniques don’t actually prevent cancer coming back, although they often help people feel better. See page 38 for some relaxation techniques
- Taking time to just reflect about life, your experiences, values and priorities can be helpful. Sometimes keeping a diary can be a way of ‘getting it out’ and feeling OK. Be generous and congratulate yourself on what you have coped with
- The Cancer Helpline is a valuable source of information: call **13 11 20** to find out more about local support groups and brochures which may be helpful.

“ I wrote a journal every day and documented all the treatments, food taken, medicine prescribed, feelings etc and still continue with the diary. This gave me back some power and a feeling of control. ”

5. Complementary Therapies:

Complementary therapies are therapies which are used in combination with standard medical treatments. Many of these treatments have been scientifically evaluated and found to be of benefit in terms of mood, control of symptoms and pain. Examples include relaxation therapy and guided imagery. Alternative therapies are therapies which are used instead of standard medical treatments and have not been scientifically evaluated. Some of these substances can be harmful:

- You and your medical team are ‘the team’. You have to work out what matters to you and your family. You don’t have to accept treatments to please other people
- Think about whether you would accept advice from this person about **a)** the type of surgery you needed, **b)** the particular chemotherapy drugs, or **c)** the amount of radiotherapy you needed. If the answer is “*No, of course I wouldn’t accept their advice, they’re not qualified in that area*”, ask yourself if the same applies to accepting their recommendations about vitamins or alternative treatments

- Discuss with your doctor, pharmacist or dietitian any treatments which you are taking, including ‘natural’ preparations such as herbs and vitamins
- Get information. Work out what suits you. Memorial Sloan Kettering Cancer Centre is the largest cancer hospital in the world. It is based in New York and they have a great internet site devoted to complementary and alternative therapies. You can access it via the website, which allows you to select any topic and find evidence-based information: www.mskcc.org/mskcc/html/11570.cfm
- Cancer Council NSW website also has some information on complementary therapies. You can access it at: <https://www.cancercouncil.com.au/>
- Be prepared to respond firmly to anyone who is applying unwelcome pressure. Saying things like: *“Thanks for that, but I think we’re cruising along with a number of things at present. I’ll let you know if I need more information”* or: *“I’ve got a heap of information about all of those things, and I am checking out what suits us, so I think we’re sorted at present.”* This allows the person to hear clearly what you want without offending them, when in fact they have been trying to be helpful.

✓ *Get reliable information. Talk to your doctor*

✓ *You choose what suits you*

6. Going Back to Work:

The decision to return to work is a very personal one. For some people their work gives a valuable sense of self, identity and achievement, and they miss

the social contacts if they are unable to work during treatment. For others it can be stressful, and work is really about earning an income. If your treatment has been very difficult, or you had other health problems before the cancer, it may not be possible to return to work. Making a decision about this can be very painful, and this is made worse if it means concerns about money. Remember that there are experienced health professionals who are familiar with these sorts of issues and talking with a Social Worker for example can often help you to feel more comfortable about your situation.

“Hasten slowly back to work if you can. There is a lot of re-building going on in your body after chemo or radiation (or both). Be patient and let it happen. You’ll know when you are strong enough – and you will need stamina as much as strength. If there is one thing most of us survivors will have learned, it is to put everything in perspective. Most of the time, work can get along just fine without us. We’ll be back, but only when we are ready!”

- Planning your return to work is important. Think carefully about the timing. For example, if fatigue is a problem for you, and your job is quite physically demanding, consider if it would be possible to resume part-time work. Consider the timing of your return, for example, if you work in the airline industry, returning to work at the beginning of end-of-year school holidays may not be optimal as this is usually a peak travel time

- Plan in advance what you will discuss with colleagues about your diagnosis and treatment. Sometimes even writing a note can be useful. For example, a primary- school teacher who had been absent from school for three months because of her cancer treatment sent a letter to the parents of the children when she returned to school. The letter told parents that she had been away sick, and that she had missed the children, and was sorry that her absence had been disruptive for them. She went on to say that she was now well, and how much she was looking forward to getting back to work. She listed several exciting projects she wanted to do with the children, including some excursions. Doing this helped her to feel in control, to “set the tone” of how she wanted to handle things, and gave a clear message to parents that she wanted the focus to be on the children and their progress, not her health.

“Whatever happened to you last week, last month, last year, you can never change. But you can change what will happen from today.”

7. Worrying About Recurrence:

Completing treatment is really just the first step in the next part of your life. For many people the most challenging part is thinking about the future and worry about whether the cancer might come back. For some people the fear of cancer coming back is a major concern that affects their quality of life and interferes with relationships. This is an area where researchers are working to try to find out the best ways to help people cope.

Everyone is different, and what works for one person may not work for another. Think about which of the strategies below might be helpful for you, remembering that if this is really troubling you, professional help might be what you need, from a psychologist or psychiatrist. A lot of people think that seeking professional help is a sign of weakness, and that you should just ‘get on with it’. However, research has shown that completing treatment is a challenging time, and most people who seek counseling feel that it is helpful:

- Sometimes the struggle to get rid of the worry is more of a problem than the worry itself. It can be useful to ‘allow’ yourself to have the worrying thoughts. For example imagine going on a car trip with an unwanted passenger (in this case, the passenger is the thought about the cancer coming back). You just can’t shake off this passenger. Swerving and driving the car fast won’t make him fall out, nor does shouting at him. So... maybe just drive safely, knowing he is there. If you are aware that he could say something, well, that is what unwanted passengers do. But if you try to pretend, he isn’t there and he speaks up you may feel startled or angry. This technique is really about accepting that some anxiety about the cancer is normal and is part of your life now, rather than fighting against it
- Try to think about stress and worry differently. Doesn’t stress help you keep deadlines and keep organised? Doesn’t stress make you check the traffic ahead and avoid running into the cars ahead if they stop suddenly? Maybe stress and worry are just part of the deal of having had cancer – not something you would choose, just part of the deal
- Focusing on things within your control such as general lifestyle factors (e.g., exercise) and attending review appointments can also be helpful in managing fears about recurrence
- Relaxation techniques can be an added part of coping with your fears and a good way to recharge. These are discussed in detail on page 38.

8. Coping with ‘Chemobrain’:

Having treatment with chemotherapy can be associated with feelings of ‘being in a fog’ and having difficulty with memory. Doctors now recognise that this is a real and potentially distressing side-effect of treatment. Currently we don’t know exactly what causes the problem, or even who is most likely to have problems after treatment. It is an area where there is a lot of research. One very reassuring thing is the area of research called ‘neuroplasticity’ which has found that we can create changes in our brains even as we age. In general, being active and doing things like reading, doing interesting things, or even learning a foreign language have been suggested to ward off dementia! Physical exercise seems to help with maintaining brain function too!

The following suggestions seem really basic, but they can be helpful if you feel that you have ‘chemo-brain’:

- Be prepared to pace yourself. Break tasks into manageable chunks and do things one a time instead of a million things at once
- Cut out distraction when you are under pressure. For example, turning off the radio when driving can help with concentration
- If you are in a shared workplace you may find that headphones or soft background music at your desk can reduce the distraction of background office chatter or phones ringing
- If you are finding you are not sharp under pressure, let phone calls go through to voicemail. Then you can listen to the message when you feel calm, think about the content of the message and work out how you will respond, and call back when you are relaxed and have plenty of time. Always have a pen and paper next to the phone and write down the person’s name, the day and time and what they are saying every time you answer the phone
- Plan activities for when you know you are likely to be most fresh and alert
- Keep lists (and remember to look at them!)
- Repeat information – for example if being told someone’s name, repeat their name out loud. Creating a mental picture or link can be helpful to remember. For example, if you meet a tall woman called Hilary you mind picture Mt Everest in your mind and think of Sir Edmund Hilary. This technique has been used successfully by people who have exceptional memories
- Try to remain calm if you can’t remember things. A memory you chase will elude you every time. Allow it to ‘drift back’ and it almost invariably will. Be gentle with yourself and allow yourself to accept that momentary lapses are common for everyone
- Be prepared to have a couple of stock lines if you are taxed: *“Oh, a senior moment – don’t you hate that!”* or *“I can blame it on chemobrain. Now at least I have an excuse!”*
- Gently persist with activities and interests, such as reading, gradually increasing the task complexity. Over time you are likely to find that you can focus on a whole chapter or book, rather than just a magazine article.

- ✓ Use prompts like lists
- ✓ Routine helps, as does breaking tasks into smaller chunks
- ✓ Being physically and mentally active are both helpful

9. My Wife/ Husband/ Carer is Nagging Me:

Having cancer is stressful for you and the people who care about you. However, when you start treatment often there is the feeling that you are doing something about it and you can at least take some control. But for partners the sense of helplessness and uncertainty commonly persist. It is very hard to watch someone you love be unwell and feel that you can't fix it. Unfortunately, this anxiety and concern may not be expressed directly, perhaps because of concern about upsetting or placing a further burden on you. The focus of the concerned partner is often on food and weight, and this can lead to serious tension within a relationship. Think about whether the following scenario fits with life at your place, for example if you are the man who has been treated for cancer:

“ Post treatment 3 to 6 months are much tougher than treatment. ”

Your wife says	You think	She responds	Your reaction	She says
<i>“What do you want for dinner?”</i>	I can't face anything, everything tastes like cardboard but you say: <i>“Whatever you think”</i>	By preparing you your (before cancer) favourite – pasta	Feel overwhelmed – why has she given you such a large portion? <i>“I can't eat all that”</i>	<i>“You'll never get better if you don't eat”</i>
<i>“You have to eat all that's on your plate”</i>	I just can't face a big meal, but say: <i>“I didn't feel like it”</i>	<i>“But you know your weight is down. You've got to eat”</i>	<i>“Get off my back, I'll eat when I can”</i>	<i>“I don't know why I bother”</i>
<i>“Do you want to go out for a drive?”</i>	I'd rather just watch football on TV but you say: <i>“Well if you want to”</i>	<i>“Look I'm just trying to stop you mooching around”</i>	<i>“But I'm tired”</i>	<i>“Well you've got to make an effort you know”</i>

The real problem is not just the food or level of activity. It is about fear and helplessness, and of course lack of communication. The following tips can be very helpful:

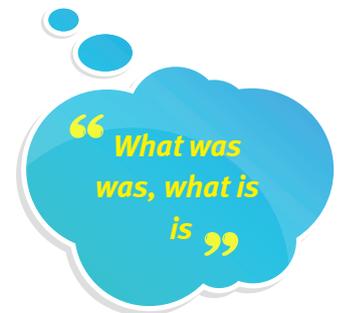
- Discuss your nutrition goals openly with your dietitian and friends and family who are providing you with support.
- Ensure those providing you with support with your nutrition intake are aware of the symptoms you are experiencing including pain, loss of appetite and taste changes.
- The way you feel about eating and drinking now can change over time as you recover from your treatment. Don't be afraid to experiment with different foods and drinks.
- You may find it helpful to talk to someone who has been through this treatment before.

10. I Just Don't Enjoy Things Anymore:

Coping with cancer is tough, and feelings of anxiety and sadness are normal. For most people these are temporary, and settle over time. However for a significant number of people (and their partners) anxiety, sadness and depressed mood don't improve over time, and in some cases can affect ability to cope with work, relationships and life generally. The good news is that effective treatments for anxiety and depression are available, and health professionals such as your General Practitioner, a psychologist or psychiatrist can assist you:

- Sometimes people think *'well of course I feel a bit down, it's been a tough time'*. The difference between just 'feeling down' and being depressed is that depression tends to persist over time without really getting better. The person who is depressed just can't enjoy things the way they used to, and sometimes it can be so bad that they feel hopeless or helpless. This can even extend to feeling worthless or guilty about the impact of the cancer on their family. People who are depressed often have trouble sleeping, and typically wake up early in the morning. If you are depressed, you can find it hard to motivate yourself and feel that you have no energy – everything feels like a bother
- The reasons some people become depressed and others don't are complex. Depression can run in families and if you have ever been depressed in the past you may be more likely to experience depression after a diagnosis of cancer
- Any serious illness can trigger depression even if the person has never been depressed before, and the chance of becoming depressed is higher still if the illness is associated with pain, fatigue or other symptoms
- Things like problems in relationships, not having a lot of support, financial concerns and other stress such as unemployment, family illness or loss can increase the risk of becoming depressed. Being younger and having dependent children can make coping with treatment more complicated and can also be associated with depression. It isn't rare for someone who has faced a lot of difficult life circumstances to find that cancer is 'the straw that broke the camel's back'
- Treatments for depression are generally very effective. Medication isn't always required, and 'talking therapy' with a psychologist or psychiatrist usually helps. The talking therapy often consists of discussing practical concerns, identifying unhelpful thinking patterns, and helping challenge unhelpful thoughts
- Medications for depression are usually very effective, and they do not cause a problem with cancer treatments. Sometimes people are concerned that they might be addictive, or that they will have to take them forever. Antidepressant medications are not addictive. They don't make people go crazy. They don't cause people to rush out and commit suicide. It is true that some people taking antidepressants have harmed themselves, but the scientific evidence indicates that severe depression can lead to desperate thoughts and acts, and that antidepressants don't actually cause this in someone who hasn't had those thoughts beforehand

- There is more information about depression in: ‘Cancer: how are you travelling?’; a copy of which is included in this resource suite. You may also find it helpful to go to the beyondblue website which includes stories written by people who have experienced depression: www.beyondblue.org.au/index.aspx?
- In Queensland, the Cancer Council offers free telephone-based counseling for anyone affected by cancer. This might be for you or a family member or carer. You can access this service during or after treatment, which is delivered by nurse counsellors and psychologists, by calling the Helpline on 13 11 20.
- You can also access RBWH Oncology Psychology during your treatment period or if you have psychological concerns that are linked to your cancer experience and you are ongoing RBWH patient (receiving reviews by your treating teams). RBWH Oncology Social Work is also accessible during your treatment period. Just ask to be referred when you are being reviewed.



- ✓ *Anxiety and depression are common*
- ✓ *They are not a sign of weakness*
- ✓ *Treatments are effective so don't put up with being anxious or depressed*

11. What if I Can't Stop Smoking?

Some people who get head and neck cancers have smoked, others have not, and we are not sure of the reasons for this. What we do know is that for people who have had a cancer diagnosis, quitting has many benefits for cancer recurrence, other health conditions, and quality of life. But quitting is easier said than done for most people!

- It can be useful to think about smoking and what you like about it, and then to think about what you don't like about it and try to weigh up each side. Having had cancer is a pretty good motivation for most people to stop smoking
- Many people see smoking as a way of managing stress – when quitting, it can be helpful to build other ways of reducing stress (see relaxation techniques on page 38, for example)
- There are some medications which are useful to help with cravings for cigarettes, and many people find benefit from nicotine replacement therapy or patches
- You can discuss these options with your General Practitioner. The Quitline website provides information about quitting smoking: www.quit.org.au
- You may not be aware that in fact a large number of people stop smoking without any treatments at all – they go ‘cold turkey’

- You may also not be aware that most people have several attempts at quitting before they achieve their goal of not smoking. So rather than become disheartened that you have quit but then started smoking again, think about each time you quit as being like a rehearsal for the ‘final performance’ when you are able to quit for good
- Another helpful technique can be planning for a date when you will quit and discussing this with family and friends in advance. If they know about your plan they can support you and making a public statement about it can be a great motivator to go ahead with your plan. Quitline www.quit.org.au can also provide ongoing support for a quit attempt.

✓ *Most people don't quit smoking the first time they try*

✓ *Having a lot of attempts at quitting increases your chance of eventual success*

12. Can I Drink Alcohol?

Alcohol is used by a large proportion of the Australian population, and although considered to increase the risk of developing some cancers, many people who have never consumed alcohol do develop cancer.

In general, maintaining a healthy weight and good nutrition are important for anyone treated for cancer, and being aware of the scientific evidence about alcohol is also important. The National Health and Medical Research Council (NHMRC) www.nhmrc.gov.au/health-advice/alcohol says that for healthy men and women, drinking no more than two standard drinks on any day reduces the lifetime risk of harm from alcohol-related disease or injury. Reducing the alcohol, you drink may help to reduce the risk of developing further cancers and other diseases, but it is difficult to say by how much. You can discuss this with your oncology specialist or General Practitioner.

13. I'm Just so Tired:

It is well known that many people who receive chemotherapy and/or radiation treatment often experience symptoms of cancer related fatigue (tiredness). These symptoms can persist for quite some time after treatment has finished and can affect one's quality of life by making it difficult to undertake the activities a person might want or need to do. However, there are many things that can be done to help manage this situation.

It is helpful to know that cancer related fatigue can change during the course of treatment. Fatigue can also be influenced by the type of treatment being received.

There are treatable factors that can contribute to cancer related fatigue. Some of these include anaemia, poor sleep, physical changes to the body, emotions, poor nutrition, reduced activity levels and other health problems such as infections, or those affecting heart and lung function. It is always worth mentioning this to your doctor to check if any tests need to be done or if there are any other treatments you need. Identifying specific factors that are causing you to feel fatigued can help you manage it successfully.

Very commonly no obvious cause for fatigue is found, other than having less strength, which then leads to feeling more tired, and this leads to losing fitness. This is called 'deconditioning'. If you have become deconditioned your efforts to get going again can feel very difficult, and the natural tendency is to ease back or rest, which of course perpetuates the problem.

Being active can help to reduce fatigue both during and after treatment. Current research suggests that cancer patients who exercise regularly experience better outcomes and have fewer side effects from treatment, including feeling less fatigued. There is even some evidence that exercise might reduce the chance of cancer coming back! See page 26 for exercise information and an exercise program.

Your energy levels may also be improved by changes to your diet. A high protein high energy diet can also assist in re-building lost muscle to help regain your strength and activity.

✓ *Being physically active has been shown to reduce fatigue*

“ I am 63 years of age and no longer see myself as bullet proof but have a healthy respect for life and appreciate the simple things in life. Cancer has made me aware of the gift of good health and I no longer take it for granted. ”

14. Confidence, Body Image and Sexuality:

Body image is used to describe the way a person feels about their body, how it works, and how they fit in with society. Having any serious illness, even if the physical effects are not obvious to others, can affect our body image. Because of the treatments for head and neck cancer, many people feel self-conscious and feel that their body image is affected.

Sexuality is closely related to body image, and doesn't just involve having sex. It's about our relationships, how we think others see us and how we see ourselves. What was previously normal is changed, sometimes dramatically, but what can we do about it?

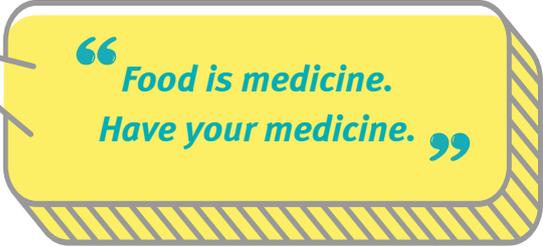
- The first step is to recognise that this is an issue
- You don't have to pretend everything is OK if you feel upset. It can be incredibly frustrating if people try to reassure you that 'you look fine. I didn't even notice your skin' when you feel dreadful. Be prepared to take the initiative and say that it has been tough coping with physical changes
- Talking generally helps. Talking with supportive friends and family members, or members of a support group. A key message is that for most people body image concerns do become less difficult over time
- Communication is really important. If your partner is concerned about avoiding physical contact until you are well, it is easy to misinterpret this as meaning that they are no longer attracted to you. Talk about what you feel and what you need
- Making time to share some fun activities, enjoying physical closeness, holding hands or cuddling are important first steps in re-establishing your sexual relationship
- The Cancer Council has some excellent resources which you can order or download from the internet. The web address is:
https://www.cancer.org.au/assets/pdf/sexuality-intimacy-and-cancer-booklet#_ga=2.226049626.1173817511.1661417859-955089417.1626244520
Sexuality, Intimacy and Cancer
- For women who have become menopausal following treatment with chemotherapy, there can be problems with vaginal dryness because of the lack of estrogen. Several treatments can help with this
- If your confidence, body image or sexuality are causing concern, it is important to talk to your oncologist or General Practitioner as specialist counseling by a psychologist or psychiatrist can be helpful.



Dietary and Swallowing Advice After Treatment

Many patients experience continued side effects in the first few weeks after treatment. These can include:

- Difficulty swallowing
- Pain
- Fatigue.



*“ Food is medicine.
Have your medicine. ”*

This can result in missing meals or having smaller portions, and not getting enough nutrition or fluid. Nutrition and fluid are very important to:

- Prevent weight loss
- Help improve healing
- Prevent dehydration
- Aid recovery from side effects.

If you are concerned that you are not eating or drinking enough or you are losing weight, you should report this to your doctor and dietitian. If your pain is not well controlled, discuss this with your doctor.

If you are experiencing difficulty swallowing, you should discuss this with your speech pathologist. Signs of swallowing difficulty include coughing or choking when eating or drinking. The speech pathologist can assist by:

- Assessing your swallow function
- Advise on the most appropriate foods and drinks to prevent risk of choking
- Providing strategies to improve swallowing safety and/or prescribing exercises for strengthening your swallowing function.

Short Term Side Effects:

Every patient recovers at a different rate, but it can often be a few weeks until the side effects start to improve.



“ If your throat feels like it has razor blades mounted in it, others have also experienced this. ”

Sore Mouth or Throat:

Many will still experience a sore mouth or throat due to ulcers. Until this improves you may still require:

- A softer diet such as a liquid, pureed or minced diet
- High protein high energy milk drinks and/or supplements e.g. Sustagen, Ensure Plus, Fortisip.

Taste Changes:

Keep trialling foods and flavours, as you never know when your taste may return.

You may start to notice your taste buds returning gradually, which can help with your appetite. Different tastes may return at different times. It is best to keep testing out a wide range of foods, not just your old favourites.

Long Term Side Effects:

Some side effects can persist for months after treatment, and some may be long term changes you will need to adapt to.

“ Food and eating are such a huge part of normal life. It is only when each meal is dreaded that you realise the effect it has on how you interact with your partner, and how it controls normal social interaction. ”

Dry Mouth:

Lack of saliva means you may need to:

- Continue to have softer foods
- Use sauce/gravy to moisten foods
- Have a drink with meals
- Sip water/fluid frequently during the day.

Ask your healthcare professional if there are any products that can assist in managing a dry mouth.

Dentition:

It is recommended that you consult a dentist who specialises in post radiotherapy dental care. He/she can give you additional advice and care for your mouth and teeth.

If you had your teeth removed prior to radiotherapy, ask your radiation oncologist when you can have dentures fitted. Often this can be 6 months after radiotherapy. Putting dentures back in too early can cause ulcers.

Tube Feeding:

Some patients may have a tube for feeding during or after treatment (such as a gastrostomy or nasogastric tube).

It is important to maintain regular contact with your dietitian and speech pathologist after treatment. They can help you to start eating again.

As you recover from the side effects, you will be advised on which foods will be safe for you.

As your eating improves, you will be advised by the dietitian on reducing your tube feeds.

Tube Removal:

Again, the timing of tube removal will vary between individuals.

- If you are managing enough food and fluid orally and maintaining your weight, your team may recommend tube removal
- A small number of people require a feeding tube long term due to severe ongoing swallowing problems.

Long Term Dietary Advice for Survivors:

Key messages for reducing your risk of cancer after you have fully recovered from your treatment are:

- Maintain a healthy body weight
- Ensure a variety of foods from the main 5 food groups (meat/fish/poultry, dairy, fruit, vegetables, breads/cereals)
- Limit high fat and high sugar foods to assist in maintaining a healthy weight
- Limit alcohol
- Exercise regularly.

More information on this topic can be found from the Cancer Council: www.cancercouncil.com.au/wp-content/uploads/2021/11/Living-Well-After-Cancer-2021.pdf.

Further General Information:

The Cancer Council helpline provides useful support with counselling services or patient support groups. Phone 13 11 20.



Advice on Communication Difficulties

You may experience changes in your communication skills depending on the diagnosis or treatment prescribed. Areas of communication change can include:

- **Voice** – This can include changes to voice quality or volume
- **Speech** – This can involve any difficulty clearly articulating words
- **Language** – Involves difficulty understanding others, reading, writing or speaking.

If you have any difficulties in these areas, contact your Speech Pathologist who can assist communication difficulties through assessment and management by:

- Advice on voice care and strategies to improve voice production
- Exercises to improve speech clarity
- Strategies and therapy to improve verbal and written communication.



Caring for your Oral Health

Changes to Your Saliva, Mouth and Teeth Following Cancer Treatment

Maintaining excellent Oral Health is vital for patients who have received treatment for head, neck and mouth cancer. This is particularly so for patients who still have their own natural teeth and have received radiation therapy.

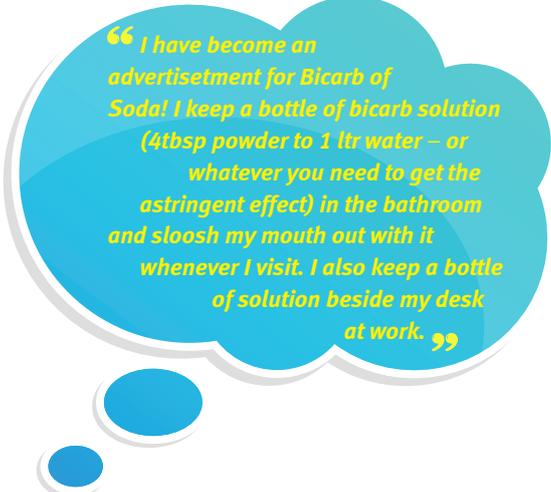
Radiotherapy adversely affects the jaw bones, the blood vessels, the teeth, especially the salivary glands, resulting in a severe reduction in the quantity of saliva. Orally this may lead to three significantly adverse side effects:-

- Saliva failing to neutralize (buffer) the acids that are produced from bacteria in your mouth that interact with foods that you eat, potentially causing very rapid decay, known as Radiation Caries.
- Saliva failing to supply the calcium and phosphate ions that are in normal saliva that re-mineralise the outer layer (enamel) of the teeth. The absence of these ions causes weakening and loss of the enamel surface of the teeth. The teeth can become most difficult to restore permanently and are physically weakened and aesthetically displeasing.
- If teeth in the area of radiation treatment ever have to be extracted, there is a potential for the bone sockets not to heal. This serious complication is called Osteoradionecrosis.

Actions You Can Take:

You may already have established good dental habits during your treatment which is great, but this needs to continue at an even higher level now that you have finished treatment. The best treatment is **PREVENTION**. Always think:

- ✓ *Thirty minutes of prevention a day, spread over the course of the day, every day, for the rest of your life*



“I have become an advertisement for Bicarb of Soda! I keep a bottle of bicarb solution (4tbsp powder to 1 ltr water – or whatever you need to get the astringent effect) in the bathroom and sloosh my mouth out with it whenever I visit. I also keep a bottle of solution beside my desk at work.”

Your Daily Regime for Excellent Oral Hygiene:

- Rinse with sodium bicarbonate (Baking Soda) mouthwash before and after eating. (A teaspoon of Baking Soda in a glass of water; leave in the bathroom and change daily)
- Use fluoride toothpaste (1,000ppmF) *after every time you eat* to reduce tooth decay
- Use dental floss once **DAILY** for the rest of your life
- Stimulate the **FLOW** of saliva by continually chewing sugar-free gum
- If you take liquid medicines, ensure they are sugar free
- Limit the number of times (the frequency) you have sugary food and/or drinks between meals.

Please Remember:

Your teeth are just miniature knives and forks! Like when you have to ‘wash-up’ your own knife and fork after eating, you also have to ‘wash-up’ your teeth knives and forks, using the bristles of a soft toothbrush – and using fluoride toothpaste. (And to floss all your teeth once a day.)

Products and Systems You Should Really Use. Three are Totally Essential:

1. The most important preventive system involves having individually made mouth guards that fit over the natural teeth and are used to supplement the calcium, phosphate and fluoride ions that are not supplied by the irradiated salivary glands. The fluoride ions are in Gel form and are always used in the morning, while the calcium/ phosphate ions are in a Mousse form and are used last thing at night. Keep the mouth guards in for only four minutes. Then spit out, but don’t wash out. These products are obtained from your dentist.
2. Last thing at night use a smear of GC’s ‘*Tooth Mousse*’ in the mouth guards to supply extra Calcium and Phosphate ions to the enamel surface.
3. Obtain a supply of Neutral Fluoride Gel (9,000ppm F⁻) from your dentist to use as a smear in the mouth guards and use them once only in the daytime.

The Fluoride Gel is always used separately from the Calcium/ Phosphate Mousse as these ions will react and bind together with each other if used together, and thus there will be no free ions available to re-mineralise your saliva or your teeth.

Other Useful Products:

- Sometimes you may have to use fungal and bacterial plaque control solutions like the non-staining, alcohol-free 'Curasept's' Chlorhexidine Gel, mouthwash or toothpaste. This can be purchased from Curasept, phone: 08 8272 6196
- Another helpful toothpaste/gel is 'Denta-Med' that lubricates the actual gums and mucosa and inside the cheeks. This can be purchased from www.denta-med.com.au or phone: 03 9646 8456
- You may find products like alcohol/detergent free 'Biotene's Oral Mouthwash or artificial saliva/ mouth lubricants helpful.
- GC's pleasant Dry Mouth Gel is a lubricant that also helps retain dentures.
- The use of a good A.C. power electric toothbrush to assist with cleaning would be most beneficial. It is mandatory to use **soft** or **extra soft** bristles.

L. J. Walsh. Clinical assessment and management of the oral environment in the oncology patient. Aust Dent J 2010; 55 :(1 Suppl): 66-77

N. Andrews, C. Griffiths. Dental complications of head and neck radiotherapy. Part 1, Part 2. Aust Dent J 2001;46:(2):88-94, 2001;46:(3):174-182

“Dental care generally is well worth the effort. Flossing 3-4 times a day is great – and necessary since we don't have a lot of saliva to wash away the stuff between our teeth. I think the figure is that normal guys produce up to seven litres of saliva a day to spirit gunk away, whereas we produce a fraction of that. So we have to help out a bit. I also have Tooth Mousse I got from my dentist which I apply each night (just another routine). I see my dentist each 6 months for a check-up. I'm delighted to say that those teeth I have left are in better nick than they have been for most of my life!”

Caring for Your Oral Health:

Some cancer treatments, particularly radiation, can leave you with a dry mouth. This decreases the comfort of your mouth and leaves your teeth vulnerable to decay. Saliva plays an important role in protecting your teeth, so without saliva you need to have excellent oral hygiene. The dentist will add some protective products to your dental regime such as fluoride.

Long Term Side Effects of Radiation:

The long term side effects of radiation which can affect the oral cavity include:

- **Dry mouth** (Xerostomia)
- **Radiation Caries** (Rapid decay)
- **Trismus** – Reduced opening of the jaws
- **Osteoradionecrosis (ORN)** – Poor bone healing.

Dry Mouth:

After radiation you may notice a rapid and profound decrease in saliva. Depending on the location of the radiation field, this decrease could be permanent. Good saliva plays an important role in protecting teeth. With a decrease in saliva, good oral care becomes vitally important to ensure the good health of your teeth and gums.

Radiation Caries:

Teeth in the high field of radiation become weaker as a result of radiation. Without good oral care they can decay more rapidly. This is a preventable problem.

Trismus:

A late onset consequence of radiation can be fibrosis of the muscles which work to open your mouth. This causes a gradual reduction in how wide you can open your mouth. Exercising these muscles as early as possible in your radiation treatment can keep these muscles working well. Try opening your mouth as wide as you can ten times and repeat this set three times each day. This should be started in week 1 of radiation and continued as a daily ritual forever.

Osteoradionecrosis (ORN):

Following radiation, bone within the radiation field may lose the ability to heal if a tooth is extracted. This is a permanent risk which does not decrease with time. For this reason, good oral care is essential to reduce the need for future extractions. If an extraction is unavoidable, your dentist will liaise with your radiation oncologist or a dentist experienced in cancer care, before any extraction can take place. Ill-fitting dentures which cause ulceration of the mouth could also lead to ORN. You must have any denture sore spot treated immediately. This also remains important in the long-term.

Replacement of Teeth:

You may have had teeth removed as part of your preparation for radiation. A prolonged healing time is needed before dentures can be fitted. An upper denture can be fitted six months after radiation and a lower denture can be fitted twelve months after radiation.

In some cases, a crown, bridge or even an implant may be an option. We recommend this decision is delayed for a year following radiation to allow your oral health to stabilise. Implants should only be considered with input from your surgeon and/or radiation oncologist.

How to Care For Your Oral Health Following Radiation:

- Brush after each meal. If you are still tender from cancer treatment use a super-soft toothbrush eg. Toddler toothbrush
- At least every night (more often if you wish) use Neutrafluor 5000 toothpaste as this will provide a fluoride treatment for your teeth. Following radiation, this high fluoride toothpaste must be used at least once/day forever. Remember, spit but don't rinse. You need to leave some on your teeth to soak in and protect them
- Floss (or use interdental brushes) daily
- Keep mouth moist with regular sips of water. Mouths are not meant to be dry. You need to work at keeping it moist to maintain a good oral environment
- Optional extra: Tooth mousse is a good product which you can brush on to your teeth at night before bed. It is thought to enhance the protective effect of the fluoride. Available from your dentist.

Suggestions to Keep Your Mouth Moist:

- Regular sips of water
- Chew sugar-free chewing gum
- Dry mouth gels/ rinses
- Xylimelts – a lozenge that adheres to your gum and slowly dissolves, producing some saliva output. Available at RBWH pharmacy
- Avoid spicy, acidic, abrasive foods. Limit caffeine and alcohol.



Exercise – Getting Back on Track

Head and Neck radiation and surgery can cause a number of side effects. Many of these can be lessened with physiotherapy.

Skin Care:

Your skin may become worse initially after treatment. Continue the skin care regime instructed by your nurses.

When doing your neck and shoulder exercises, you may be more comfortable wearing clothing without a collar, particularly if your skin is still sensitive. However, if you are exercising outside, wear suitable hat and clothes to give sun protection to the treated area.

Neck and Shoulder Movement:

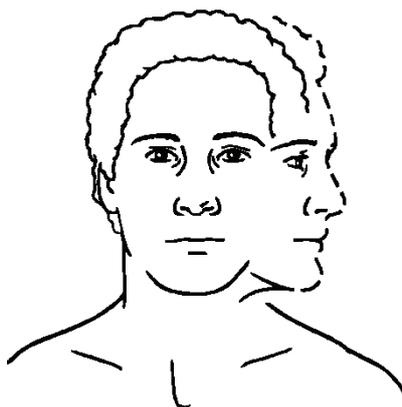
To achieve the best outcome, it is imperative to continue with the following exercise program for at least 6 months after the completion of your cancer treatment.

Focus particularly on the movements that feel restricted.

The following exercises are general exercises to help you regain full movement of your neck and shoulders. Do these exercises every morning and evening.

(If you have had surgery, you may need more specific exercises depending on the extent of the surgery, so please check with your physiotherapist. Read more later in this section.)

Exercise 1:



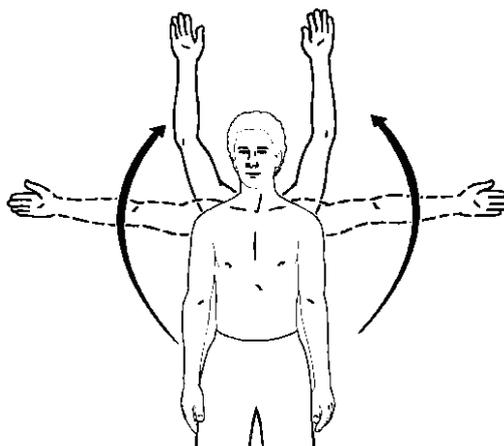
- Turn your head as far as you can to the left
- Gently hold this position for 30 seconds then turn back to your starting position
- Repeat to the right.

Exercise 2:



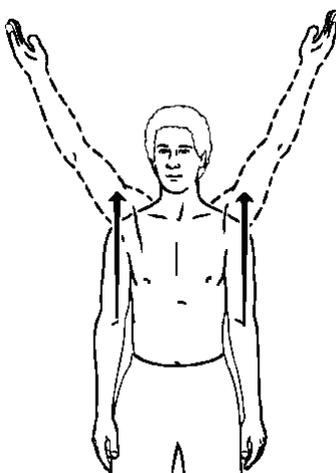
- Tilt your head toward your left shoulder while looking straight ahead. Gently hold this position for 30 seconds, then return to your starting position. Repeat to the right.
- Gently stretch at the end of each movement for at least 30 seconds. You should only feel a comfortable stretching feeling.
- If you cannot tolerate the stretch for 30 seconds, start with stretches for 10 seconds, and increase the length of the stretch each week to build up to 30 second stretches, for example:
 - Week 1** – stretch for 10 seconds
 - Week 2** – stretch for 15 seconds
 - Week 3** – stretch for 20 seconds
 - Week 4** – stretch for 25 seconds
 - Week 5** – stretch for at least 30 seconds.
- It may be easier to start doing these stretches lying on your back. If you feel pain with any of your exercises, you might have gone too far with the movement. Start again and slowly go to the end of the movement. Should pain persist or you are unsure – stop and contact your physiotherapist.
- Measure your progress with your neck movement each week. A helpful way to do this is to lie on your back with a small cushion or folded towel under your head, and your shoulders relaxed. Turn your head to the left as far as you can. Note what you can see. Repeat this turning to the right.
- Repeat this exercise weekly by laying on the same bed with the same pillow or cushion or folded towel under your head. Each week you should be able to turn your head further. If your movement is becoming more restricted, contact your physiotherapist or talk with your doctor about seeing a physiotherapist.

Exercise 3:



- Lift your arms out to the side and up above your head. Slowly lower your arms back to the side of your body. Repeat 10 times.

Exercise 4:



- Lift your arms forward and up above your head. Slowly lower your arms back to the side of your body. Repeat 10 times.

Surgery to your head or neck could lead to restrictions of your neck and shoulder movement.

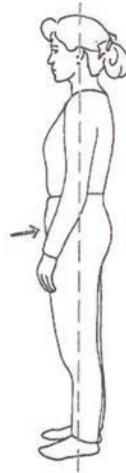
In some cases, the surgery might have damaged nerves and your doctor might have informed you about this. For some people, there will be ongoing limitations to shoulder range and function.

In either case a physiotherapist can assess your neck and shoulder movement and give specific advice to assist you to regain function. An occupational therapist might also be able to help modify activities or prescribe equipment to make everyday tasks easier (e.g. if you are having difficulty lifting arms high in the air to hang out the washing). If you have not seen a physiotherapist or occupational therapist, ask your doctor to refer you.

Restricted neck range of movement may result in difficulties with driving. If you have restricted movement of your neck, you should consult with your Doctor before resuming driving.

Sometimes treatment can affect your jaw. You might have pain in your jaw or cannot open your mouth widely. Please contact your speech pathologist or ask your doctor to refer you to a physiotherapist if this is the case.

Posture:



Your posture may have changed because of the treatment (which may include surgery). Regaining a good posture will help to lessen pain and long-term joint problems.

Try sitting or standing tall, by straightening your back and drawing your abdomen in, with shoulders back and relaxed and your chin gently tucked in. Hold this position gently for 30 seconds. Practice this often throughout the day. Try each week to increase the time you can hold this good posture. Correcting your posture in a mirror or having another person remind you of your posture can also be helpful.

Swelling:

After surgery and/or radiation there can be swelling in the area of treatment. This is normal and should settle.

If you have had neck dissection surgery involving the removal of lymph nodes, or if you have had radiotherapy to the neck you may be at risk for developing lymphoedema. This is swelling due to accumulated lymph fluid and will not easily settle, whereas swelling after treatment will settle after a few weeks.

If you notice swelling or fullness under your chin, in your neck or face that persists, or changes to your speech or voice quality and/or swallowing, ask your doctor or healthcare team to refer you to a physiotherapist, occupational therapist or nurse who has had training in lymphoedema management. They will assess you and assist you with specific treatment for this swelling.

The lymph fluid can be pumped from the area by activation of the muscles in your face and neck. Contracting the muscles of your face and eyes with different facial expressions, moving your tongue in all directions, and chewing can be very helpful as well as continuing with your neck and shoulder exercises.

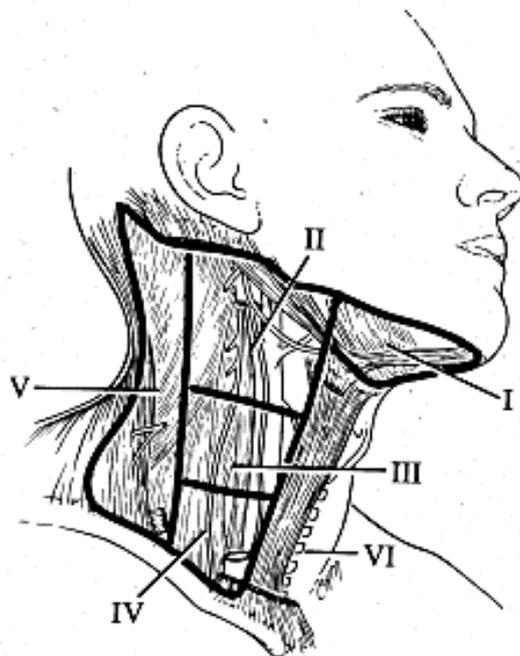
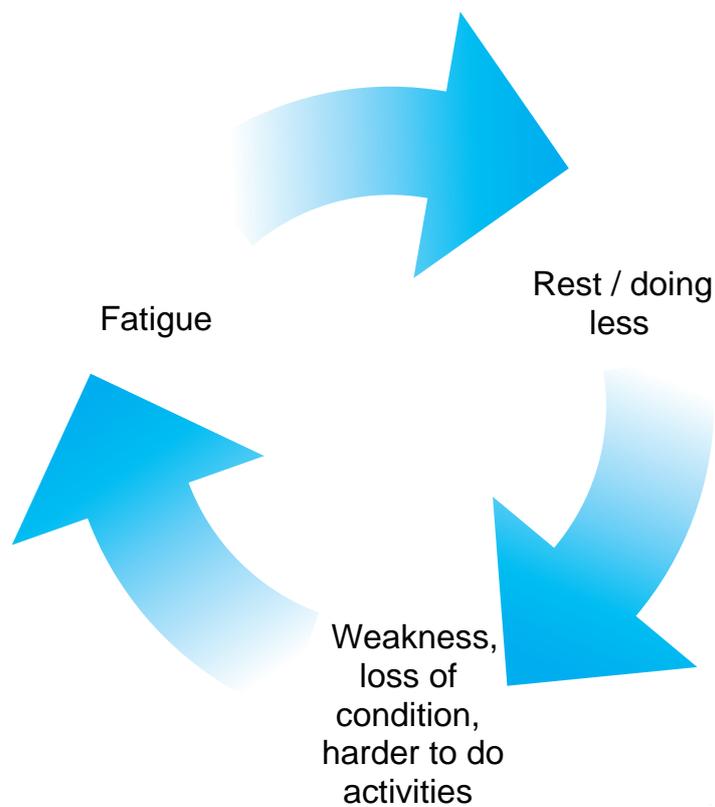


Figure 1: Cervical Lymph Nodes—Division of cervical lymph nodes by levels. Level I = submental and submandibular group; level II = upper jugular group; level III = middle jugular group; level IV = lower jugular group; level V = posterior triangle group; level VI = anterior compartment group. Reprinted, with permission, from *Arch Otolaryngol* 17:601-605, 1991. © 1991, American Medical Association.

Fatigue and Physical Activity:

Fatigue is a common side effect of any cancer treatment. Rest or reduced physical activity (doing less) can create a vicious cycle of doing less, leading to weakness, and finding it harder to do things, and as a result, feelings of worsening fatigue.

Vicious Cycle of Fatigue:



Exercise Guidelines

Start doing some physical activity during your treatment and continue long term. This might be a short walk, which you could increase by a few minutes every week, or going up a few stairs.

Doing some activity is better than none, and more activity is generally better than less (up to levels meeting national physical activity guidelines) ^[2].

The Clinical Oncology Society of Australia (COSA) recommends all people who have had a cancer diagnosis to return to normal daily activities as soon as possible and to participate in **regular physical activity** and aim for:

- At least **150 minutes** of **moderate intensity** or **75 minutes** of **vigorous intensity** aerobic exercise each week e.g: walking, jogging, cycling, swimming.

AND

- 2-3 resistance exercise sessions e.g: lifting weights or body weight resistance exercise (e.g: wall press, sit to stand) targeting the major muscle groups. ^[1]

By not doing some physical activity during and after treatment, fatigue may worsen and lead to a loss of fitness and physical ability. Keeping as active as you can during treatment can lessen the feeling of fatigue, alleviate psychological distress and improve quality of life ^[1]. Exercise helps to improve our physical function (aerobic fitness, muscle strength and ability to do things).

Regular exercise is associated with reduced risk of developing comorbid conditions such as cardiovascular disease, diabetes and osteoporosis.

Exercise and Recovery:

Research in breast, colorectal and prostate cancer has shown that doing some exercise, particularly being more active after cancer treatment than before being diagnosed, may reduce the risk of cancer recurrence and death. The link to exercise in head and neck cancer is not yet as clear, but exercise during and/or after cancer treatment has been shown to be safe and gives many benefits.

Some Potential Benefits of Exercise During and/ or After Cancer Treatment: ^[1]

Exercise for cancer survivors should include aerobic and resistance activities.

Aerobic Exercise:

Aerobic exercises are low-impact and activities that use large muscle groups such as swimming, walking, treadmill exercise, cycling/ exercise bicycle. Choose an activity that you enjoy and feel good about doing. Exercising with others can build confidence and motivation to stick to it. Consider also your own situation:

- if your immunity is low, avoid public facilities for that period of time

- if you have problems with balance, walking, coordination, dizziness, or reduced sensation in your feet, avoid exercises like cycling that require good balance and coordination, or consider a stationary exercise bike instead
- if you have any spread of cancer to your bones, avoid high-impact or contact sports.

To start, simply aim to do some light exercise 3-5 days each week e.g., going for a walk. Try to increase the length of time you exercise each week. You should gradually build up to a level that causes you to breathe a little heavier, but be able to continue a normal conversation e.g., walk briskly while still being able to talk comfortably. This is regarded as moderate-intensity exercise.

If you are still experiencing symptoms such as nausea, shortness of breath, fatigue, or weakness, do the amount of exercise that you can manage – some exercise is better than none. Short bouts of exercise e.g. 3-5 minutes at a time, repeated across the day with rest periods, may be easier. Daily exercise is important while you regain fitness.

Resistance Exercise:

Resistance exercise is important to gain strength and can improve bone density. It can include using free weights (such as a 200g tin of tuna or a 400g tin of tomatoes), machine weights and body weight. Again, if your balance, coordination or sensation is affected, or if you are experiencing dizziness, do not use free weights alone – it is safer with a training partner. This kind of exercise should be done 1-3 times a week, with rest days between sessions. Start with small weights e.g. 200g and slowly increase!

General Advice:

Whatever exercise you choose, try to include some aerobic and resistance activities in your program. Start at a level you can manage, and progress at your own pace. It is very important to start every exercise session with a warm-up and finish with a cool-down and stretches.

Even though your cancer treatment has finished, you may still experience good days and bad days. Particularly on the bad days, it is important that you try to do some exercise but lower your goals on that day – don't try to do the amount of exercise that you can achieve on a good day.

It is important to gradually increase your physical activity and exercise. Eventually, you should aim to do some moderate-intensity exercise for 30 minutes on most, preferably all, days. Try to be active every day as much as you can. Regular vigorous exercise also gives extra health and fitness benefits ^[2].

If you want help and advice in starting or progressing your exercise program, your doctor can refer you to a physiotherapist. It is important that the physiotherapist has a thorough understanding of your cancer, how it was treated and any side effects you have experienced. This will affect the exercise program and advice that will be suitable for you. They may communicate with your oncologist to develop a suitable individual program to meet your specific health needs.

Choose activities or forms of exercise that you enjoy. Being active is one of the most positive steps you can take in your recovery from treatment!

Examples of an Exercise Plan

Use these examples as a guide only. Your exercise program needs to be specific to your situation.

If you have questions or are unsure about where to start, contact your physiotherapist before starting an exercise program.

1. Early after finishing treatment, still feeling fatigue and weakness:

Monday

- ★ Neck and shoulder exercises (*morning and evening*)
- ★ Walk around the block (*8 minutes*).

Tuesday

- ★ Neck and shoulder exercises (*morning and evening*)
- ★ Shoulder exercises holding 200g weights
- ★ Wall squats.

Wednesday

- ★ Neck and shoulder exercises (*morning and evening*)
- ★ Walk around the block (*8 minutes*).

Thursday

- ★ Neck and shoulder exercises (*morning and evening*)
- ★ Walk 5 minutes in shopping centre, coffee with friends, use stairs to car park to return to car rather than travelator.

Friday

- ★ Neck and shoulder exercises (*morning and evening*)
- ★ Wall push-ups
- ★ Lunges.

Saturday

- ★ Neck and shoulder exercises (*morning and evening*)
- ★ Walk around the block (*8 minutes*).

Sunday

- ★ Neck and shoulder exercises (*morning and evening*)
- ★ Deep breathing exercises.

2. Five months after finishing treatment – side-effects have settled, feeling well, cleared by oncologist to progress activity back to previous level:

Monday

Gym Program:

- ★ Warm up – neck and shoulder exercises (*no weights*); Exercise bike (*10 minutes*)
- ★ Machine weights for arms; legs 3kg free weights for arms; Treadmill walking (*10 minutes*)
- ★ Cool down – stretches for arms, legs, neck; Neck and shoulder exercises (*evening*).

Tuesday

- ★ Neck and shoulder exercises (morning and evening); Pilates class (*30 minutes*).

Wednesday

Gym Program:

- ★ Warm up – neck and shoulder exercises (*no weights*); Treadmill walking (*5 minutes*)
- ★ Rowing machine (*5 minutes*); Machine weights for arms and legs; 3kg free weights for arms
- ★ Exercise bike (*5 minutes*)
- ★ Cool down – stretches for arms, legs, neck; Neck and shoulder exercises (*evening*).

Thursday

- ★ Neck and shoulder exercises (*morning and evening*)
- ★ Walk (*30 minutes*).

Friday

- ★ Neck and shoulder exercises (*morning and evening*)
- ★ Bike ride (*20 minutes*).

Saturday

Gym Program:

- ★ Warm up – neck and shoulder exercises (*no weights*); Exercise bike (*5 minutes*)
- ★ Rowing machine (*5 minutes*); Machine weights for arms and legs; 3kg free weights for arms
- ★ Treadmill walking (*5 minutes*)
- ★ Cool down – stretches for arms, legs, neck; Neck and shoulder exercises (*evening*).

Sunday

- ★ Neck and shoulder exercises (*morning and evening*)
- ★ Easy grade bush walk 3km.

References:

1. Cormie, P., et al., Clinical Oncology Society of Australia position statement on exercise in cancer care. *Med J Aust.* 2018. 209(4): pg. 184-187
2. Hayes SC, Spence RR, Galvão DA, Newton RU. Australian Association for Exercise and Sport Science position stand: Optimising cancer outcomes through exercise. *Journal of Science and Medicine in Sport* 2009;12:428-434.
3. Department of Health and Aged Care (1999) National Physical Activity Guidelines for Australians, Canberra.



To Help with Fatigue

Fatigue is experienced by a number of people during and after treatment for head and neck cancer. Fatigue can have a number of causes, however for many people a cause may not be found. It is worthwhile discussing your fatigue with your Doctor and Occupational Therapist to help identify the causes of this fatigue. Identifying the specific factors that are causing you to feel fatigued will help you to manage it successfully.

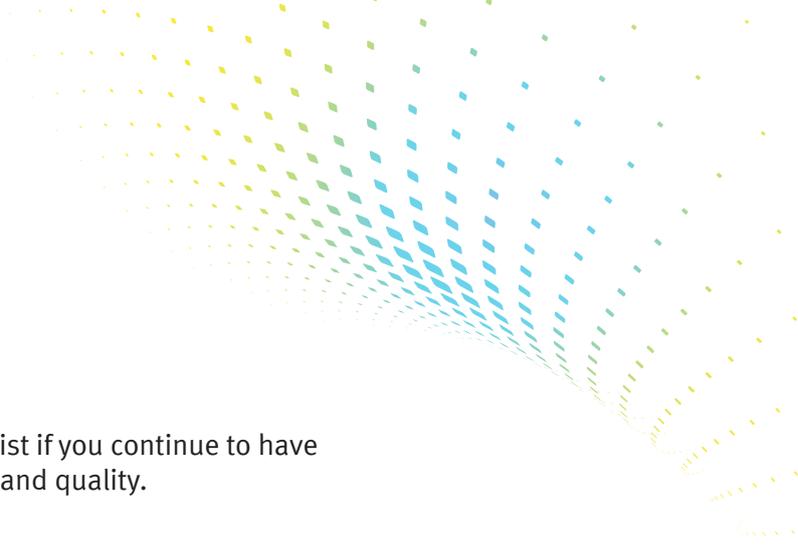
Managing Fatigue:

- **Being Active:** Can help to reduce fatigue both during and after treatment. It is recommended that you aim to do 30 minutes of moderate physical activity on most days of the week.
- **Stress Management:** Be aware of the role your emotions and attitudes play in causing stress. Avoid comparing yourself to other patients, or how well you can do things now as against before treatment. Be kind to yourself and accept help when offered.
- **Relaxation:** Understanding how to relax and having a variety of strategies available can be very helpful throughout your treatment. There are many different relaxation methods including:
 - Deep breathing techniques
 - Progressive muscle relaxation
 - Listening to calm music
 - Visualisation
 - Mindfulness.
- **Sleep Techniques:** Sleep is essential for our health and wellbeing. Research shows that most adult need 7-8 hours of sleep each night however some people may function well on less sleep than this.

Research shows that developing ways to improve your sleep patterns can help with fatigue. Poor sleeping habits can result in a cycle of low energy and ill health. Tiredness and fatigue can lead to daily naps. Frequent 'napping' during the day can then cause sleeplessness at night.

The quality of your sleep is more important than the amount of sleep you get each night in order to cope with fatigue. Here is a list of strategies to use in order to have deeper better quality sleep:

- Set up your sleep space
- Prepare your mind and body for sleep
- Use your bed for sleeping and sexual activity only
- Maintain a consistent bedtime and wake time

- 
- Minimise napping
 - Talk to your GP or Occupational Therapist if you continue to have difficulty improving your sleep pattern and quality.
 - **Nutrition:** Eating a well-balanced diet and drinking plenty of fluids is particularly important when undergoing treatment. If you are having problems with eating and/or swallowing, the Dietitian or Speech Therapist can help you.
 - **Energy Conservation:** Pacing yourself decreases the strain on your body and reduces the amount of energy needed to do tasks. It is important therefore to maintain a balance between activity and rest so that meaningful activities can be maintained. This might mean that you will need to:
 - Set priorities and realistic expectations
 - Delegate tasks or ask for help
 - Take short breaks between activities
 - Use assistive equipment
 - Adopt techniques that require less effort e.g sitting rather than standing.

Use Good Breathing Techniques:

Activities that have become difficult or tiring are more manageable when co-ordinated with controlled breathing. **Breathe in before starting an action and breathe out during the more strenuous parts of an activity.** This technique is used by weight lifters to improve their muscle efficiency. Controlled breathing can also help if you feel breathless due to tension, worries or anxiety. Breathing fully instead of taking shallow breaths while you work will help to give you more energy, improve your endurance and make you feel more relaxed.

Set Goals and Plan Ahead:

Forward planning and setting goals, can help to reduce stress and improve activity levels and life satisfaction. Some goals are easier to achieve while others will take longer. Writing down realistic, achievable goals and reviewing your progress may help. **Use a timetable to schedule your activities** into those that are required to be completed daily, weekly, fortnightly and monthly. Review whether any of these activities can be done less frequently. Remember to include time for resting and time to complete tasks without rushing. **Prioritise tasks. Plan time for pleasurable activities,** (e.g. a holiday or an outing), which can also restore enthusiasm and feelings of well-being. Be aware of the times in the day where you may have more or less energy and plan activities accordingly. Closely monitor the days when you feel particularly fatigued during your treatment cycle, so that you can prepare for the next cycle. Be flexible to allow for unexpected events.



Stress and Relaxation Techniques

Stress happens to everyone, every day, as we cope with events, respond to situations and make decisions in life. Not everybody experiences stress in the same way, or for the same reasons. Some people thrive on certain levels of stress in certain situations (e.g. work) as it can be stimulating and motivating for performing tasks effectively, while others may find that same level of stress very difficult to cope with. They may experience fatigue, poor concentration, irritability, withdrawal, insomnia and/or erratic eating habits. When we feel worried, frustrated or anxious, we consume a great amount of energy which can contribute to fatigue and other side effects.

Learning to manage your stress effectively has many benefits. Dealing with everyday stressors effectively helps us to cope better with the physical and mental demands that stress puts on the body, and therefore reduces its long term impact on our physical and mental health.

Relaxation Techniques

Relaxation may help you to cope with everyday stress and demands, and to gain increased quality and enjoyment of life. Relaxation may improve your energy levels and have an impact on your function in work, relationships, and concentration. To achieve the benefits of relaxation, regular practise is essential (just like any new skill you have learned in the past). There are many different types of relaxation methods (e.g. tai chi, deep breathing, music, aromatherapy). What suits one person may not suit another person.

To maintain the benefits, relaxation needs to be practised for at least 5 to 10 minutes every day, or 2-3 times a week. You may need to practise the techniques when you have some time alone free of interruptions, preferably in a quiet environment. Try not to fall asleep.

Here are some example relaxation techniques.

1. Five Minute Relaxation:

This is a simple exercise that, once learned, can be used effectively in many circumstances in very little time:

- Sit in a comfortable chair or lie down and close your eyes (try not to go to sleep – unless this is your aim)
- Imagine a personally relaxing and pleasant scene including sights, smells, sounds, and feelings
- Relax your shoulders down
- Let your arms relax on your lap/armrests.
- Relax your hands
- Allow your legs to rest on the floor (don't cross your ankles)
- Allow your neck, head/face and jaw muscles to relax

- Try not to think of anything (if any thoughts enter your mind acknowledge them and then... let them go)
- Silently say *'relax'* to yourself
- **Focus on your breathing:** Breathe in using your lower chest (a natural rhythm), then slowly breathe out. Continue to focus on your breathing. Breathe slowly – in through your nose, out through your mouth.

2. Visual Imagery (5 – 20 minutes):

Imagery encompasses all of the body's senses (*sight, hearing, touch, taste and smell*). Through consciously visualizing a scene, daydream or meaningful memory your body can become stimulated with positive feeling, allowing it to cope with stressors (e.g. pain/discomfort) and relax:

- Imagine a personally relaxing and pleasant scene including sights, smells, sounds and feelings (e.g. walking on the beach or nature walk, or imagine you are bathed in rays of coloured light)
- Or imagine yourself doing something you enjoy (for example, sailing, fishing, playing golf, walking in nature /bush walks, being in your favourite part of your garden, a holiday destination).

3. Listening to Relaxation:

Relaxation CDs or mobile applications offer a range of relaxation exercises that you can listen to in your own time to practice relaxation techniques. They can be purchased from music, book stores, or downloaded via mobile applications. Your local library may also have relaxation CD's for loan. The Cancer Council also has free relaxation CDs available.

A referral to psychology or occupational therapy may be necessary if you are not finding these techniques helpful.

“*Cancer defines who I am now as much as work and family and other major facets of my life. I have to accept that and with time this is happening. It often makes me feel sad, but it also makes me feel strong. I can now cope with anything that life throws at me. I will (as much as possible) only do things that I think are worthwhile, either for myself or others I care about.*”



Financial Assistance

Check with Centrelink whether you qualify for any benefits or pensions such as Jobseeker (you can apply for Jobseeker with a medical exemption if you are unable to work due to illness or injury) disability support pension, family allowance or a carer's allowance. You may also be eligible for a health care card which can reduce the cost of your medications or a pension travel card which can reduce the cost of public transport.

Be aware that you can only qualify for one main pension or benefit such as Age; Disability Support; Carer's Payment; Jobseeker etc. Carer's Allowance can however be paid in addition to wages or other Centrelink support payments.

Remember to check existing insurance policies that you may hold. These policies may or may not be linked with your Superannuation Fund and may be a separate insurance policy that you have taken out. Many people with a chronic illness may be able to claim benefits under insurance policies such as Income Protection; Mortgage Protection Insurance; Consumer Credit Insurance (covers loan repayments); Trauma Insurance; Life Insurance and Sickness and Accident Insurance.

If you are unable to return to work due to disability or illness, it is worth checking with your Superannuation Fund about your entitlement for their Disability Benefits or a lump sum payout. It is imperative to seek individual financial advice about these issues before resigning from work. Remember also that an insurance benefit or a superannuation lump sum may be treated as income and may reduce your Centrelink payments.

Caregiver Benefits

Finances are also likely to be an issue for those who care for you. Travel, loss of income and various out-of-pocket expenses can add up. Any financial assistance your carers receive will not only take some pressure off them, but will also ease some of the concerns you may have about the sacrifices those around you are making.

What may help – Government benefits:

- An allowance for anyone caring for an adult with a condition who requires substantial and ongoing care. There's no assets test for Carer Allowance but there is an income test
- A payment for people who provide constant care in the home of a person with a severe illness, medical condition, or a major disability. You will need to complete an income and assets test
- Please refer to the Centrelink website www.servicesaustralia.gov.au
- Another useful website is www.chronicillness.org.au where you can find information on superannuation; disability insurance; powers of attorney and Centrelink, written in simple and easy to understand language.

If you are still attending Cancer Care services as a patient on treatment, you can request to speak to a Welfare Worker about any of the above information.

What is Radionecrosis (or Osteoradionecrosis)?

Osteo (bone) **Radio** (radiation) **Necrosis** (death of tissues or cells).

Radiation therapy used to treat cancers often causes side effects. One of the rarer and more severe side effects that may occur is osteoradionecrosis (or ORN). Put simply, this is a severe radiation effect on a bone resulting in necrosis, or death, of that part of the bone. It's estimated that the risk of ORN following a high dose of radiation for 6 to 7 weeks is less than 5%. This risk will obviously depend upon other factors that will be assessed by the multidisciplinary team.

The mandible, or jawbone, is the most common site for ORN to occur. This is because the jawbone is often exposed to a large dose of radiation in treating cancers of the mouth and throat. The blood supply to the jawbone is also different to other bones nearby and reduces its ability to resist the effects of radiation. ORN of the maxilla (cheekbone) is very rare and is usually only seen after radiotherapy for cancers of the nasopharynx (back are of the nose cavity), although still very uncommon, even in this situation.

Tooth disease and tooth extractions also increase the risk of ORN. Your multidisciplinary team will assess your risk of ORN before you start treatment and also give you advice on how to look after your mouth and teeth to reduce your risk of ORN. It is very important to follow the advice of the dental team to reduce your risk as much as possible. In some situations, teeth may be extracted before you begin your radiation treatment to reduce your subsequent risk of developing ORN.

Symptoms of Osteoradionecrosis:

The symptoms of ORN can range quite widely. It may present with little to no symptoms such as a small, painless exposed area of bone to more severe symptoms such as pain, bad breath, altered taste, trismus (difficulty opening your mouth as wide as you used to be able to), difficulty chewing, difficulty speaking, or an infection that doesn't heal.

It's important to remember that the symptoms list above can be caused by other conditions, not just ORN. In fact, it's quite common to have some of these symptoms during your radiation and for the few months after you finish your treatment. The symptoms from your radiation side effects should improve during the first few weeks to months after you finish your treatment.

If ORN does occur, it will usually happen many months or even years after your radiation treatment has finished. It's important to notify your doctor if you develop these new symptoms as they could be the first signs of ORN.



“The three month wait for scans to assess the success of the treatment seemed to take forever.”

Treatment of Osteoradionecrosis:

For mild ORN, treatment is usually conservative. This means, your doctors will often try to use simple measures such as antibiotics and improving your mouth care rather than surgery. Sometimes, conservative debridement to remove small amounts of dead tissue may also be tried. Debridement is usually avoided where possible because the tissues affected by ORN often heal very poorly or not at all and debridement can sometimes make the problem worse, rather than better. Vitamin supplements such as vitamin E, may also be tried although the benefits are unclear.

In more serious cases, surgery may need to be considered to remove the part of the bone that has died. This often means removing half of the jawbone and replacing it with a bone from your forearm or fibula (the bone next to your shinbone). Hyperbaric oxygen may also be tried as an alternative to surgery or after surgery as an additional treatment. Hyperbaric oxygen treatment is described below.

ORN that doesn't improve with treatment should also raise the suspicion of recurrent cancer, as the symptoms are often similar. Your doctor will always closely monitor the situation, particularly if they are concerned about recurrent cancer.

Hyperbaric Oxygen Therapy:

Hyperbaric oxygen therapy (HBO) can be used to treat a variety of medical conditions ranging from decompression sickness and carbon monoxide poisoning through to radiation injury (ORN). HBO can increase the amount of oxygen in the recipient's tissues greater than can be achieved by breathing 100% oxygen. As an example, HBO delivered at a standard 3.0 atmosphere pressure (three times greater than the 1.0 atmosphere which we breathe at sea level) delivers 20 times more oxygen to the recipient's tissues than 'sea level' air and 6 times more oxygen than breathing 100% oxygen. This increase in tissue oxygen theoretically means that even if the blood supply to a tissue has been lost (as is the case in ORN), the affected tissue will still receive oxygen. Better oxygen to a patient's tissues in the presence of ORN can theoretically improve how well that tissue heals itself.

Each treatment (or 'dive') places the patient in a hyperbaric chamber for about 90 minutes at a pressure of 2.4 to 3.0 atmospheres. These special machines are available in Brisbane. A typical course of HBO for established ORN usually involves up to 30 treatments. If surgery is also required, some of the HBO is done before the operation, and some afterwards to improve how well the tissue heals.

Evidence for Hyperbaric Oxygen in Osteoradionecrosis:

In theory, HBO for ORN should work fantastically well! Unfortunately, clinical trials have shown conflicting results. In fact, in a study reported in 2004, patients who were randomly allocated to receive HBO had a lower rate of recovery from ORN than those who received a placebo treatment. Despite uncertain benefit in clinical trials, HBO may still be used in certain circumstances to treat ORN.

HBO to prevent ORN is also of uncertain benefit and is not routinely recommended. Since it is of uncertain benefit in established ORN, it is almost never used to prevent ORN. The other preventative measures as outlined above are more important to prevent ORN than HBO.

Complications of Hyperbaric Oxygen:

Like most medical treatments, HBO is not without its potential complications. As such, a patient and their doctor will need to weigh up the pros and cons before making a decision whether HBO is the right option. HBO is generally safe and well tolerated for most people. Most side effects are mild and reversible although more severe side effects can occur in rare cases. It's important to remember that our bodies are designed to function at "room air" oxygen level, not 20 times higher than this.

Some of These Side Effects Include:

- Reversible muscle weakness due to direct oxygen toxicity to the muscles. This can occur in up to 20% of cases and may last for weeks to months.
- Middle ear complaints, even including eardrum rupture.
- Collapsed lung (pneumothorax). This is generally rare although higher if a patient has an underlying lung condition.
- Lung toxicity due to the increase oxygen. Usually, this presents as chest tightness and cough with a decrease in lung function over time (scarring).
- Seizures due to oxygen toxicity to the brain. The incidence rate ranges from one per 11,000 to 2.4 per 100,000 treatments.
- If occult cancer is present mimicking as ORN, receiving HBO may make the recurrent cancer grow quite quickly. Recurrent cancer mimicking the symptoms of ORN should be excluded before a patient receives HBO.

Summary:

Osteoradionecrosis (ORN) is a rare but potentially serious late side effect of high dose radiation treatment.

Prevention is the best cure for ORN! Listen to the advice your treating team have given you and follow them as best you can to reduce your risk.

If you do develop ORN, the best plan to manage this will be discussed with you. Often you will have a multidisciplinary team working with you.

Hyperbaric oxygen (HBO) is one of the options to treat ORN. It works by increasing the amount of oxygen your tissues receive so they can heal themselves. The evidence for how well it works is less convincing, so the pros and cons will be discussed, and the multidisciplinary team will work out a plan that is right for each patient.

Like most medical treatments, HBO is generally safe but can have side effects.

Talk with you doctors and other health professionals if you have any further questions.



Pain Management During/ After your Chemoradiotherapy Treatment

Pain is an unpleasant sensation that almost all of us will experience at some stage in our lives. Most of the structures in our bodies can experience pain which acts as an 'early warning system'. Even though pain is a distressing symptom, it can alert us to a problem with our health so we can seek medical advice and treatment.

Cancers of the head and neck often present with pain as their first symptom. High doses of radiotherapy used to treat these cancers also often results in side effects that cause pain. Uncontrolled pain can significantly worsen quality of life in these instances. Pain can also affect our mood and ability to cope with treatment and its side effects. This section outlines some of the specific issues relating to pain associated with cancers of the head and neck region and its treatment. Remember that if you have poorly controlled pain or a change in your symptoms, consult with your treating specialists.

Pain:

As discussed, pain is the sensation we experience as the result of damage to our tissues. In the case of cancers of the head and neck, this may be due to the cancer itself (including pressure or damage to nearby nerves, called neuropathic pain), or as a result of treatment, namely surgery or radiotherapy (or both).

How do I Manage my Pain?

Controlling your pain during your treatment is important. It will help to minimise any loss of quality of life, minimise your risk of depression, help you to cope better with your treatment and maintain a realistically optimistic outlook. Managing your pain often involves multiple steps and should always be monitored by your treating multidisciplinary team.

Mouth Care:

Looking after your mouth is very important. Meticulous dental hygiene both during and after your treatment can help minimise pain and dental or gum problems. Regular mouthwash with sodium bicarbonate or salt water is also very important. This should be done at least 4 times per day, but often during the most intense part of your treatment, more than this may be necessary.

Thrush (Candida) in your mouth can occur during your treatment as a complication. It often looks like your tongue or mouth is coated in a white furry material. This can happen because the physical barrier in your mouth (your mucous membranes), are damaged, often due to radiation. Your immune system may also be impaired due to chemotherapy, anti-inflammatory steroids or malnutrition. Thrush in your mouth is painful and often happens when it's least wanted! Topical treatments such as Nilstat or amphotericin (Fungulin) lozenges can be used to prevent or treat oral thrush. More resistant cases may need stronger treatments such as a capsule called Fluconazole. Often if thrush is treated, your pain can significantly improve without changing any of your other medicines.

Skin Care:

Radiation to treat your cancer can also result in changes to your skin. Your radiation team will usually give you extra guidance on how to look after your skin and the nurses in the radiation treatment area will regularly assess your skin in the radiation field. Some creams can magnify the effect of radiation on the skin and make this burn worse, so always talk to the nurses before trying something different.

If your skin breaks down and ulcerates, you may need protective dressing applied to protect the skin while it heals. The nurses will usually apply these dressing and show you how to look after them until your skin has healed. After you have finished your radiation, zinc and castor oil cream is great to help you skin heal faster. Remember, if you aren't sure what to do, don't forget to ask the staff for advice. This will always help to minimise the pain and inconvenience of your treatment and its side effects.

Medications to Treat Pain:

Often, despite the best mouth care and skin care in the world, you will need medication to help control your pain until you have recovered from the side effects of the treatment. Sometimes these are also necessary if your cancer is causing you pain as well. Neuropathic (or 'nerve' pain will be discussed separately).

Paracetamol and Non-Steroidal Anti-Inflammatories:

Even though paracetamol may be a "gentle" pain medicine, it is often very useful to treat pain. Paracetamol has very few side effects and often can be very effective in treating mild pain either caused by the cancer, or the early side effects of radiation treatment. It can also be used in combination with stronger medicines for pain such as opioid medications (such as morphine) as outlined below.

Non-steroidal anti-inflammatory medications such as aspirin, Indocid or Naprosyn are best avoided during radiation. They may affect how quickly your mucous membranes heal from radiation and may even make these ulcers worse. They also can affect your kidney function, particularly if you are dehydrated or receiving Cisplatin chemotherapy with your radiation.

Local Anaesthetics:

Topical anaesthetics such as Xylocaine can be used with great effect to help with the pain from ulcers inside your mouth and throat. Gargling Xylocaine around the worst affected areas can help to numb the pain particularly before a meal or helping you to get to sleep. Some people find it doesn't help much where they need it to but numbs other parts of their mouth and lips. If this is the case, then don't persist with it. Remember that when your mouth is numb, you may not be able to tell if what you are putting in your mouth will damage it more (such as too hot or abrasive 'scratchy' foods), so be careful!

Opioids (Narcotic Analgesics):

Opioid (or narcotic) medications, such as morphine, are amongst some of the strongest and best medicines for strong pain such as that caused by your cancer or treatment, particularly radiotherapy. Both during and after treatment, it is likely that you will need one of these medicines to help control your pain. The dose you will need may vary substantially depending upon what phase you are in of your treatment or recovery.

This will be assessed and discussed on your routine checkups with the medical staff supervising your treatment. If you are worried your pain isn't being well controlled or you are having other issues, don't hesitate to consult with the medical staff supervising your treatment earlier. Usually, these medications are temporary and will be weaned down and eventually ceased when you no longer need them.

Opioids, like nearly all medications, can have side effects and should only be used under close supervision. Most opioids can cause constipation requiring you to also use medications to counteract this. The most common medications used in this situation are Coloxyl with Senna or Movicol. Both of these work in slightly different ways and may even be used in combination if needed. Remember that constipation can make you feel unwell and sometimes nauseous so trying to keep your bowel habit as normal as possible is important. Another way you can help is by taking plenty of fluids by mouth or through your PEG tube – remember it's easy to get dehydrated, particularly in the warmer months of the year and this will make your constipation worse. Other strategies such as increasing your fibre intake or trying prune juice can help too.

Other important side effects of opioid medications include nausea (and sometimes vomiting), tiredness or lethargy, and slow thinking or confusion. Most of these happen more at higher doses or after an increase in your dose and often settle over the next few days. Medications to help with the nausea caused by opioids are generally quite effective. These side effects are different to a true allergy, which is very rarely caused by opiate medications.

Types of Opioid Medications:

Most of these medications come in a short acting form for fast relief of pain, and a long acting or 'sustained release' form for sustained release of pain. It is quite common to require both short acting and long acting forms of opioids during your treatment. The short acting dose of an opioid is often called a 'breakthrough' dose, as it is used for pain that has 'broken through' the long acting dose of an opioid that is controlling the background pain. It is very common for the dose to change both during and after your treatment and will be titrated to match how much pain you have. The goal will always be to have you on as little as possible to control your symptoms and then reduce your dose and stop (where possible) after you have recovered.

These medications are available in different dosage strengths to adjust to the amount of pain you have. Some even come in different colours to make it easier to tell the difference between the different dose strengths. Remember that the long acting tablets (the ones with 'Contin' in the name like MS Contin and Oxycontin) cannot be crushed – they must be taken whole.

Here are some of the more commonly used opioids used for pain in their various forms:

Morphine:

Short acting: [Ordine](#) (*morphine liquid*); [Sevredol](#) (*tablet*)

Long acting: [MS Contin](#) (*available in tablet and suspension form*); [Kapanol](#) (*tablet*). Often used for your pain. Good for relieving strong pain and quite flexible for dosing as your requirements change. The suspension can be taken by mouth or put through a PEG tube.

Oxycodone:

Short acting: [Endone](#) (*tablet*); [Oxynorm](#) (*both in tablet and liquid form*)

Long acting: [Oxycontin](#) (*tablet*)

Oxycodone is also a good option for strong pain. Dose range quite flexible too but can only be taken by mouth. Be careful not to mix up Oxynorm (*fast acting*) and Oxycontin (*slow acting*) as the names sound similar.

Fentanyl:

Long acting: [Durogesic](#) (*skin patch*)

Short acting: [Actiq](#) (*lozenge*)

Fentanyl patches have the advantage of less constipation and being used as a patch on the skin which is great if you are having trouble swallowing tablets. Its disadvantages are that it takes longer for the patch to reach a steady dose than other opioid (*which isn't good if your pain is changing week to week from radiation side effects*), the patch doses are a big jump to the next dose (*not so good if you only need a small dose as they can't be cut in half*) and sometimes they don't stick to the skin very well (particularly if you are sweaty or hairy!). The lozenges aren't readily available.

Codeine:

Short acting: [Codeine](#) (*often added to other analgesics for a pain relieving 'boost' for example Panadeine Forte is paracetamol and codeine*). Codeine may be useful for more mild pain but for more severe pain, often isn't helpful or used.

Buprenorphine:

Long acting: [Norspan](#) (*skin patch*)

Norspan is a weak opioid and often not very good for pain caused by cancer or radiotherapy side effects. It is rarely a good option in this circumstance and isn't used much.

Methadone:

Despite the negative connotations with IV drug user rehabilitation, methadone is an excellent medication for very difficult to control pain. It has a very long action which can make it hard to prescribe except by only very experienced staff.

Tramadol:

Short and long acting: [Tramal](#)

Tramadol isn't used much in this circumstance either as it often isn't very effective for strong pain and can interact with some other medications (such as some antidepressants) to cause serious side effects.

Neuropathic Pain ('Nerve Pain'):

This term describes pain caused by irritation or damage to a nerve and literally means nerve-like (neuro-pathic). The pain is often described as 'burning', 'shooting' or 'electrical' pain and may result from the affected nerve "firing off" abnormally. It is often difficult to pin-point its location and may be described as affected a vague area of the body. This type of pain may be caused by a cancer if it damages or compresses a nerve in your body.

Neuropathic pain warrants special mention because it is often more difficult to treat and responds less well to opioid medication. Identification that part of your pain may be neuropathic in nature is important, as the types of medications that are used to treat it are very different to the medications outlined above.

The mainstays of treatment for neuropathic pain are medications that stabilise this abnormal triggering of the affected nerve (or nerves). Some antidepressants (such as amitriptyline or nortriptyline) or anti-epileptics (such as Valproate, Carbamazepine or Gabapentin) can treat neuropathic pain. These medications may be effective at low doses but may also require an increase of the dose to be effective or sometimes even trying a different medicine to have some effect. Despite this, neuropathic pain may be difficult to control and your doctors may need to refer to a specialised medical team to help manage your pain.

Summary:

Pain is a common complication of your cancer and its treatment, particularly radiotherapy. Good mouth care and skin care can be helpful to manage your pain. Most patients will require stronger pain medications such as an opioid (narcotic) to control their pain. These medications can have side effects, such as constipation that may require other medications to counteract the side effects. Neuropathic, or nerve pain, can be more difficult to control and may require different medications or a consultation with another specialised medical team (such as The Pain clinic).

Your medical team will monitor your pain and adjust your medications accordingly. Be sure to tell the staff looking after you if your pain control is poor as you may need your medication adjusted. Unexpected worsening of your pain may be due to other problems such as oral thrush or more serious problems such as osteoradionecrosis (see ORN section) or cancer.

Remember, if you have any questions or concerns, talk with your doctors and other health professionals.



'GO TO' LIST

Radiation Oncologist:

Radiation Oncologists are the cancer specialists who supervised the radiation component of your treatment. They will closely supervise and care for you during your treatment and often co-ordinate your follow up after you have completed your treatment and recovered from any side effects from radiation. Assessment of your response to treatment including CT scans are also organised by your Radiation Oncologist. Your specialist will also work closely with the rest of the multidisciplinary team below.

Insert the name of your Radiation Oncologist here:

.....

Medical Oncologist:

Medical Oncologists are the cancer specialists who supervised the drug treatments often given with radiation to help improve its effects in killing cancer cells. This is most commonly chemotherapy but may sometimes be an antibody treatment if chemotherapy is not an option for you. Your Medical Oncologist will also closely supervise your treatment until you are recovering from the side effects after your treatment and work closely with the rest of the multidisciplinary team. Most commonly, your Radiation Oncologist will arrange your follow up once you have finished your treatment.

Insert the name of your Medical Oncologist here:

.....

General Practitioner:

Your Family doctor will continue to have an important role in supporting you both during and after your treatment. Your specialists will keep your Family doctor informed of your progress both during your treatment and follow up. Your Family doctor also has an important role in managing your other health problems, particularly after your treatment is completed. Your family Doctor can also be a useful contact point for helping you to return to work.

Dentist:

Regular follow up with your Dentist is essential. With head and neck cancer treatment, often the salivary glands function poorly, adversely affecting the teeth so regular dental reviews are mandatory. Without ongoing, personalized dental prevention and surveillance, the teeth may decay quickly and if need to be removed, can lead to osteoradionecrosis where the jawbone fails to heal.

Cancer Care Coordinator:

We can continue to be a link for you back into Cancer Care Services to help with the coordination of post treatment care.

Nurse:

Your nurse will support you in managing your side effects post treatment.

Dietitian:

It is recommended that you continue to see a Dietitian for a minimum of 6 weeks post treatment to assist with managing your dietary intake while you still may be experiencing side effects and symptoms of your treatment. If you have a feeding tube the Dietitian will continue to monitor your feeding and weight and provide a script for your supplies of feeds. Once you have recovered from the side effects of your treatment, the Dietitian can also assist in dietary advice to maintain your health and reduce your risk of cancer.

Speech Pathologist:

Continue to assess and manage speech, language, voice and swallowing disorders after you have finished treatment.

Physiotherapist:

Help you to maintain/regain your normal level of function, particularly neck movement, with advice and exercise; provide mobility and fitness assessment and guidance, including prescription of aids if needed.

Social Worker:

Provide support, education and guidance around a range of psychosocial issues which may arise throughout treatment.

Welfare Worker:

Address practical concerns and provide information/support relating to short term accommodation for rural patients, travel subsidy schemes, financial concerns, access and external resource options e.g. Cancer foundations, non-government assistance agencies.

Occupational Therapist:

Occupational Therapy (OT) aims at promoting or maintaining health and well-being through participation in occupation. The primary goal of OT is to enable people to participate in their everyday activities as safely and independently as possible, in order to maintain a meaningful quality of life.

Psychiatrist/ Psychologist:

Help you and your family to understand and cope with the psychological impact of cancer diagnosis, treatment and recovery.

Cancer Council Queensland:

Are Queensland's leading independent organisation in cancer control and are a great source of support, information and resources. Anyone who has been affected by cancer is welcome to access telephone support via their helpline on **13 11 20**. Their website is: <https://cancerqld.org.au/index.php>.



Support Networks

Cancer Voices:

Aims to provide a voice for all people affected by cancer in Queensland. As a network of people concerned about the issues impacting people with cancer, Cancer Voices Queensland aims to work with partners to achieve change and make a difference within the community. Ultimately Cancer Voices Queensland aims to reduce the impact of cancer by promoting a better quality of life for those affected.

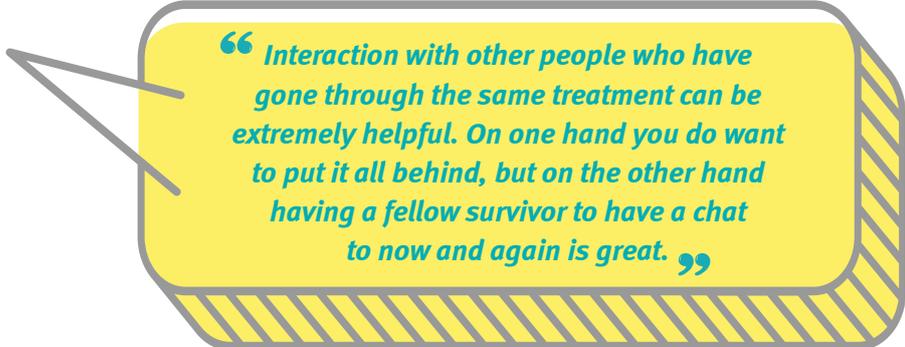
We welcome as members:

- Anyone affected by cancer; a cancer patient, survivor, family member, carer or health professional
- Any interested person.

The expectation is that members will want to engage in advocacy on behalf of those affected by cancer and in line with the Cancer Voices Queensland objectives.

Membership is free, and Cancer Voices Queensland welcomes you to join.

Visit the website at: www.cancervoicesaustralia.org.



“ Interaction with other people who have gone through the same treatment can be extremely helpful. On one hand you do want to put it all behind, but on the other hand having a fellow survivor to have a chat to now and again is great. ”

Brisbane Head and Neck Cancer Support Group:

This support group is a group of people who have been through the treatment of a variety of Head, Neck and Mouth Cancers.

We offer a safe environment and an opportunity to meet with people who have been, or are currently in a similar situation to yourself. We discuss what to expect and methods of dealing with the diagnosis and treatment as you return to an active life afterwards. You can call the Cancer Council Helpline on **13 11 20** for more details of when we meet.

For those people who live out of Brisbane, please contact the speech pathology department at your local hospital to find out about any support groups in your area.



This page is for you to fill out on completion of your treatment. If you have any questions when trying to complete this section, please contact your Cancer Care Coordinator on 0437 346 605.

My Radiation Oncologist at RBWH is:

.....

My Medical Oncologist at RBWH is:

.....

My Surgeon at RBWH is:

.....

Now that I have finished treatment, which is my closest hospital?

.....

Who is the person or facility in my local area that I should contact if I have questions or concerns about my post treatment and follow up care?

.....

My local Cancer Care Coordinator is:

.....

My next appointment is (time and place):

.....

It is important that you keep a book or notepad with you so that you can record any questions you may want to ask when you next see your Doctor or other health care professional (e.g. Dietitian).



Queensland Government

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