"Emotional Side Effects" The impact on those having treatments for brain cancer, their carers and loved ones

People often say they will never forget the moment they first heard the word cancer. The diagnosis is a significant life crisis for most people, their families and loved ones. It is often a new and uncertain experience, a life altering event.

There will be similarities in people's experiences and responses, but there will also be differences depending upon the type of tumour, location and stage of disease, and course of treatment. There will be also be differences in how people respond depending upon your unique life situation and how it affects your lifestyle, your hopes and dreams.

A range of emotions are common for you and your loved ones - sadness, fear, anger, numbness and/or disbelief. All of these are completely normal feelings to experience and may fluctuate during the course of treatment.

You may find yourself worrying more, irritable, "on edge", and struggling to sleep well. A loss of confidence in your health or loved one's health and the constant waiting – waiting for doctors' appointments, waiting for test results, waiting to see if the treatments have provided the hoped for responses – can be very stressful and unsettling.

Sometimes the intensity and demands of treatments is so fast-paced and overwhelming, that the emotional aspects of wellbeing are not given time or attention. Some patients, families and/or carers may feel reluctant to discuss this area of their well-being, however your emotional responses can affect your quality of life, so this is a really important area of your care.

State Cancer Councils are a helpful starting point for up-to-date information on the range of individual, telephone, face-to-face, group, peer and web-based support options available (see www.cancer.org.au or call 13 11 20).



A cancer diagnosis means adjusting to a 'new normal' in your life.

After treatment... getting back to "normal" life can seem tricky. Support groups and 'life after cancer' programs can help connect with others to share experiences and learn tools to live the best life you can. This can reduce the sense of isolation and normalise your responses to your experiences.

Loved ones and carers may share many of the same feelings and responses as the person receiving care. They may also feel pressure to 'keep it all together' while being 'strong and positive' – not always easy or possible!

Carers and loved ones often find that their emotional responses also fluctuate over the roller-coaster of care. Some people find that dealing with their own emotions and the emotional responses of those around them can be as challenging as the physical demands of treatment – and there's no instruction manual! Everyone processes information and adjusts to information at a different pace, and it's common for people to feel like they're at loggerheads or not always 'on the same page'.

Good communication and professional help can play an important role in helping people work together to support each other despite these differences. Keeping relationships as healthy as possible is vital to the physical and emotional health of everyone.



Carers need support too Carers are key members of the care team

Carers provide crucial support to the person receiving treatment, be it practical, physical, emotional, personal or financial. Many people are very concerned about the impact of the illness on those around them, particularly children in their life. For a partner, child (including an adult child), parent or friend, they may feel helplessness as they watch on.

Being able to talk and share support is important for everyone.

The Emotional Side Effects: Worries, Anxiety and Depression

The "emotional side effects" of brain cancer are as important to address as the physical side effects

Worries and anxiety are common and may be compounded by uncertainty about the physical side effects of treatments and impact on future plans and goals. Physical signs of anxiety may include racing heart, shortness of breath and feeling "on edge"; for some people these feelings may escalate into feelings of panic.

If these symptoms or worries are hard to control and make it hard to cope with daily life, it's important to seek help as effective treatments are available. Many people will find their mind filled with "what ifs", so learning strategies such as mindfulness, relaxation breathing and maintaining their perspective (for example, with the use of cognitive behavioural therapy) can really make a difference as can help with getting a good night's sleep).

1 in 6 people will experience depression in their lifetime

For those with a cancer diagnosis, it rises to more than 1 in 4. It's no surprise that carers are also at an increased risk of depression.

- The risk of depression is likely to be higher for those having more treatments, more invasive treatments, those having ongoing treatments, and those with a less hopeful outcome.
- More physical side effects such as pain, fatigue, headaches and seizures increases risk, as does a greater change in one's usual cognitive and physical functioning.
- The location of some brain tumours and use of some medications and treatments can also directly influence mood (for example, mood fluctuations associated with steroid medications).

Feelings of sadness and grief, a loss of confidence in one's health and future, and changes to usual lifestyle can be difficult to manage.

Side-effects of the illness that influence day-to-day life, such as not being able to drive or exercise, can have a dramatic impact on one's independence, sense of self, as well as one's mood. The duration and costs of treatment, numerous appointments, liaising with many different health services and professionals, and even managing all the paperwork such as dealing with Medicare or insurance companies, can all add pressure and affect your ability to cope.



We all have times when we feel low or sad, and it can be hard to know if we are actually experiencing depression. So what are the warning signs of depression?

- Emotional changes may include feeling constantly flat, feeling worthless, helpless, guilt and losing interest in areas of our life that we have previously enjoyed (including relationships and intimacy). We may find we lack motivation, and avoid activities or people. Worry often goes hand in hand with depression as it can wear us down. Sometimes a sense of hopelessness leads to thoughts such as *"it's all too hard"* and *"what's the point of all this?"*, or even thoughts of self-harm. It is vital you tell others and get immediate help if you notice such thoughts or feelings (see below).
- Sleep habits may also change. We may find ourselves sleeping more or unable to get to sleep, unable to stay asleep or waking early, all of which contribute to feelings of fatigue and reduced motivation.
- Physical changes such as changes in your appetite, weight and energy levels may be due to treatments, but may also be due to depression or made worse by feelings of depression.
- Behavioural changes may include avoiding activities or people, doing less (apathy), changes to how one communicates, and taking less care in your appearance. They may be associated with the impact of treatments but may also be affected by how you are feeling about yourself
- Cognitive changes can occur with the diagnosis of a brain tumour for example, memory, repeating oneself, confusion, concentration, problem solving and multi-tasking can be affected by our mood, and can affect our ability to "think straight", organise ourselves and make plans. Tasks that we have managed easily in the past may seem too hard, and we may find it harder to take on new information and make decisions, finding it harder to concentrate and remember things.

There are also changes which can result from the brain cancer - sudden changes in emotions, anger, irritability, unpredictable, impulsive or inappropriate responses and behaviours, which can be challenging for the person experiencing them as well as those around them. It can be hard to know whether some of the changes are due to depression, anxiety or the brain cancer, so getting expert input can help understand the causes and interventions that may be able to help.



What help is available?

The good news is that just like with anxiety, there are effective treatments for depression. Talk to your team - your doctors, nurses, Clinical Nurse Consultant, or social worker and ask about what services and interventions are available. Your General Practitioner can be a great support - they will be able to discuss a referral to a counsellor or Psychologist and can also discuss the role of medication.

Sometimes the thought of seeing a counsellor or psychologist might seem like just another appointment, but it can be well worth the effort. Research evidence indicates that psychological interventions may improve the quality of life and well-being of those dealing with cancer.

Get information...

Websites such as Beyond Blue

(www.beyondblue.org.au) and the Black Dog Institute (www.blackdoginstitute.org.au) provide lots of information on signs of depression and treatments. Beyond Blue provides a helpful fact sheet on "Brain tumours, anxiety and depression".

If this article has raised concerns for you please call your local mental health team or contact Lifeline (ph 13 11 14 or www.lifeline.org.au); if you feel in immediate danger please ring for an ambulance or go to your local hospital.

*References are available on request.

A cancer diagnosis is a new and uncertain experience that involves thinking about strategies you may not have considered before. Many forms of support and help are available – seek and ask for help - it can really make a difference.



HEADWAYHEALTH offers confidential counselling and interventions for patients, couples, carers, young adults and families throughout their cancer care. Concerns may vary during diagnosis, treatment and post treatment.

Our team of Clinical and Consulting Psychologists are all experienced in cancer care and are Medicare providers. We work with you to identify your main concerns and develop targeted strategies to help manage them and improve your quality of life.

Strategies may assist with:

- Changes to one's health, functioning and lifestyle
- Coping with treatment
- Depression, low mood and fatigue
- Anxiety, stress and living with uncertainty

Interventions are based on best-practice research evidence that supports the effectiveness of interventions that use Cognitive Behaviour Therapies (CBT), mindfulness and other therapeutic techniques. Strategies involve non-drug treatments and are "goal-focused", so typically involve 3 to 10 appointments.

- Communicating with others and children
- Intimacy / body image
- Survivorship what now?
- Living with loss and grief
- Support for carers and families

Nutrition & Cancer Clinic

Myths vs Facts.

Everyone knows about the importance of a healthy diet but cancer can change your nutritional needs. Talk to an Accredited Practicing Dietitian at the Nutrition and Cancer Clinic.

- Weight loss/gain?
- Maintaining appetite and energy
- Cancer busting diets: fact or fiction?
- Reducing side-effects of treatment
- What about supplements?



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HEADWAYHEALTH'S team of Clinical & Consulting Psychologists offer clinics at Frenchs Forest, Hornsby, Crows Nest and SAH Wahroonga.

You may be eligible for a GP Care Plan, Private Health fund or Medicare rebate.

For further information:

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Headway Health



Committed to Bettering the Lives of those Affected by Cancer and Other Health Concerns