



Throat Cancer Foundation

'Why so many with throat cancer dread Christmas'

Press Release

'Eat, drink and be merry,' is the commandment that most people live by when it comes to Christmas.

However, for those living with throat cancer, it can be the most dreaded time of the year as what we all take for granted, such as eating and drinking at social events, has been cruelly taken away from them as a result of the gruelling cancer treatment and very often life changing side effects they are left to live with.

Those diagnosed and dealing with cancer of the throat, mouth or neck are presented with many challenges when it comes to facing Christmas dinner or social events during the festive period.

They may have had their salivary glands destroyed as a result of the treatment. Or part of their tongue, teeth or throat removed. Maybe they had the ability to eat removed completely and have been fitted with a feeding peg instead. They may be alive, but for some they are overwhelmed with feelings of, 'what's the point?' What they once enjoyed before has now been taken away from them by a very cruel cancer.

If they're lucky, they can eat, but most will find it a difficult laborious process. Food can take a long time to chew to make it soft, or it may even uncontrollably fall from their mouth. Then there's the constantly having to hold napkins or towels to deal with dribbling fluids now unable to be contained. And if they try to do all this in a public space they also have to endure judgemental or sympathetic stares from people ignorant of what the person is struggling to do. That is something they take for granted. It all adds to the stress someone with a throat cancer is already feeling.

Trying to live as normal a life as possible with a throat cancer at Christmas time is hard and for some the thought of going out and even trying to eat, drink and be merry is too much, so they simply don't do it. Many with throat cancer describe the crushing social isolation they feel they during the festive period.

Even having a Christmas dinner with their own families is a difficult process for them to deal with. Their families will understand but might get upset at watching a loved one struggle to

eat a simple meal - even if it's been pulped and made soft. It's frustrating because there is nothing they can do or say will help. For everyone concerned it's not the type of festive time it should be.

Single, mum-of-one Tracey Longmuir, 45, gave a searing personal account of the brutal struggles she faced after life-altering treatment from stage two tongue cancer in 2014, and the depression that followed as a result.

Tracey, from Lincolnshire, often still feels anxiety from fear of choking in public and as a result of her treatments, no longer has a desire to eat food.

She said: "My little boy was only two-years-old when I started my radiotherapy. I was self-employed at the time as a dog walker and the owner of a doggy day care centre so I ended up losing my business.

"The last six months of that year was horrific. I remember setting myself a goal that year that by Christmas I'd be able to eat properly. I failed.

"I ended up having to cook it and then couldn't eat it without blitzing it. It was emotionally shattering.

"I remember drinking Baileys as that night and then woke up the next day to a mouth that was so sore and covered in ulcers and blisters, I was devastated. It was the beginning a few very dark months, which fell into a depression and anxiety for a couple of years at least.

"By March time I was quite bad so had to see a doctor for anti-depressions and Cognitive Behavioural Therapy (CBT).

"It was the following Christmas by the time I was able to chew meat without worrying too much about choking as long as it was smothered in gravy.

"The festive period was really difficult for me. I completely fell out of love with food. I still have no drive or desire to eat but I know I have to."

Tracey, who was just 39 years old when she was diagnosed tongue cancer, also found herself battling from anxiety when it came to dining out with friends.

She began to avoid eating with her toddler son as he would panic if she began choking on food.

Tracey, who is given support by the Throat Cancer Foundation, said: "The social side became very difficult because I can't talk and eat at the same time.

"It becomes very restrictive in what you can and can't do, and that adds to the mental pressure of what you're left with.

"Then I had my son, who at two years old was learning how to eat with knives and forks and eat properly, and I wasn't good for him to sit beside me and learn from.

"For a year and a half, I didn't eat with him, I'd sit and tell him what to eat and what to do and that caused a lot of friction for us.

"Then when I did sit with him, I'd find myself choking on food and that was a real worry for him, watching his mum struggle. It was a very negative experience."

Tracey was also scared to eat alone for fear of choking or in case she had to ask waitresses for extra water and sauce.

“The worst part of the anxiety was from choking and not having anyone there,” Tracey admits. “Then there was the embarrassment of other people seeing how difficult it was for me to eat.

“It started to become a bit of a joke, where I’d put my hand up if people were talking to me while I was eating, just so they knew I’d heard them and to give me time to finish eating.

“Even now I still have a real dread of eating. I try to forget and carry on as normal but it’s not nice.

“I still have that emotional turmoil. No-one explains that the new you won’t like food anymore, and that it won’t taste the same and it won’t look the same to you.

“You almost just have to be prepared that this is going to happen.”

For many of those who have battled throat cancer, they are left with a sense of loss that something most of us take for granted has been taken away.

Quite often patients are left feeling an immense sense of shame or embarrassment at no longer being able to chew properly, dribbling or dropping food in public, or simply being unable to ask for help from a waitress to assist them in some way.

Fiona Morris told how her father’s struggle to eat and drink after throat cancer became a “constant strain” on his day to day life, leaving him unable to sit and enjoy a meal like he used to so easily be able to.

She is dreading this Christmas because of having to watch her father endure him watching his family enjoy food while he’s unable to.

She said: “My Dad was diagnosed with throat cancer in 1999 and he’d massive problems with swallowing food, coughing, choking, while swallowing.

“He always carried water to relieve his throat as he to found it hard to produce saliva. The food texture seemed to change for him too.

“This year he was fitted with a peg tube during the summer and will never swallow liquids food or medication ever again. He’s completely nil by mouth. His eating has always been a strain on him his day to day life never mind social end of things.

“It’s awful seeing him now all that he’s been tough and survived to be left without the privilege of been able to sit and enjoy a meal.

“We have no idea what we’re going to do with our Christmas dinner this year.”

Rebekah Smith, a senior dietician at University Hospitals Birmingham, helps to support patients who have developed late side effects of radiotherapy treatment such as increased difficulty swallowing and osteoradionecrosis.

She said: “Many patients can be left feeling angry, frustrated and fed up. Some patients feel ‘got at’ and being ‘nagged’ by family members regarding eating and drinking.

“This can cause tension with friends and family members who are trying to show the patient that they love and care for them but can often be too much for the patient who physically cannot eat/ do anything more than they already are.

“Christmas is a time that is full of socialising with friends, family and work colleagues and normally involves eating and drinking.

“A number of patients find it uncomfortable eating and drinking around other people following treatment or have certain dietary requirements that can make the patient feel apprehensive about eating at restaurants/parties/ friend houses.

“Some may feel envious that they can’t eat and drink the way that they used to.”

Rebekah has given tips to loved ones of throat cancer patients on how they can help support them during this difficult time of year.

They are:

- Ringing restaurants ahead to see if they can provide smaller portions or altered textured diet e.g. pureeing food

- Seeing what foods are available that are a consistency that they patient can manage e.g. trifle can be made with just jelly, custard and creams, offering mashed potato as well as roast, ensuring vegetables are well cooked and can be easily mashed

- Ensuring there is plenty of sauce to go with food e.g. gravy, custard, brandy butter, bread sauce (made need thinned out with extra milk/cream) etc

- Let the patient choose what they want from a variety of different of different foods at a Christmas rather than piling everything up on a plate to them

- Encourage the patient to go out and socialise and don’t add any pressure to eat and drink- remind the patients it’s about being with friends and family and not the eating and drinking. They want to spend time with the patient and are not worried if they eat or drink while they are with them. The patient may want to eat before they go out.

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Editor’s Notes: About – Throat Cancer Foundation:

The Throat Cancer Foundation was founded in 2012 by oropharyngeal cancer survivor Jamie Rae. Following his treatment and recovery, Jamie was concerned by the lack of resources and support available to people facing throat cancers and established the charity to provide what was missing: information and reassurance for those dealing with throat cancers.

The charity is dedicated to reducing the impact of throat cancers on individuals and wider society. It offers support, and aims to ensure that anyone affected, including the person who has cancer, their friends, and their loved ones, has access to the most up to date information available regarding their illness, the available treatments, and what to expect in recovery.

The foundation’s work is guided by a team of leading cancer experts and consultants working in the research and treatment of head and neck cancers. The Throat Cancer Foundation is also a founding member of HPV Action, which is a collaborative partnership of

50 patient and professional organisations that are working to reduce the health burden of HPV.

Website – www.throatcancerfoundation.org