

Don't look away

When the cure is disfiguring and disabling the care must be supportive and sustaining

➔ Peter McIntyre

In the second part of our series on *Living with the consequences*, survivors of head and neck cancer talk about the social isolation and despair of living with mutilated faces and struggling to talk, chew and swallow. Head and neck teams will fail their patients unless they go beyond check-ups for recurrence, and address their patients' needs for support and solidarity.

At the age of 36, married with three young children, Christine Piff was diagnosed with squamous cell carcinoma in her sinus and maxilla. She was treated with radiotherapy and chemotherapy, but the cancer could not be eradicated. There followed a total maxillectomy that took away half her palate and her upper teeth.

"To me it was a total nightmare," she says. I couldn't speak, I couldn't communicate with people. I used to run and hide behind my sitting room door when I saw people coming down my drive. It was the most horrendous experience I think a human being can ever have."

And it was about to get worse. Three months later the cancer had returned. She had a further operation and this time she lost an eye.

"I couldn't understand what was happening to me. Nobody had prepared me for the emotional shock of facial disfigurement or facial difference. I just withdrew into myself. Because I had three children, I had to live my life for them."

It was two years before she had a facial prosthesis, because "they thought I was going to die

anyway," says Piff. "My first prosthesis was attached to the bridge of my glasses so when I took my glasses off, I took my facial prosthesis off as well. That was a living nightmare."

Later she had an arrangement by which a powerful magnet locked her facial prosthesis onto her intraoral obturator – the prosthesis that had replaced her maxilla and teeth.

Seven years after her operation, Christine Piff did a TV programme in the UK about living with facial disfigurement. She was overwhelmed by letters from other patients and their carers – 700 in one postal delivery alone. In response, she launched a support group, *Let's Face It*, to help people rebuild their lives. (<http://www.lets-face-it.org.uk/>)

"A lot of people don't like the word 'disfigurement', but you need honesty too. We have mutilated faces. They take away eyes, jaws, noses, ears, cheeks, the floor of the mouth, tongues. It is like being totally invaded, someone cutting out your soul. Your face is you – it is your identity. We try to fill that gap and say you are still a normal human being.



A face of hope. These portraits of Henry de Lotbinière have become a rallying point for people around the world with similar problems who have been encouraged by his obvious charm. They were painted as part of a project in which patients with facial cancer, deformity and trauma damage have their portraits done before, after, and occasionally during, surgery to help them deal with their disease. Diagnosed with a malignant salivary gland tumour in 1987, de

Lotbinière, a barrister, underwent more than 14 operations over 15 years. Touched by his *joie de vivre* and infectious enthusiasm, his colleagues raised money to set up the Lotbinière centre at the Facial Surgery Research Foundation – Saving Faces – where research and clinical trials are conducted into new treatment strategies for oral cancer. For more information, see www.savingfaces.co.uk

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“Then you are on the road to reconstruction, either through plastic surgery or you go down the other route where you have prosthetics, where you sit for hours while they reconstruct your face and make spare parts. It is a formidable journey that does not stop. Every couple of years I have a new reconstruction procedure.”

Not all oral or pharyngeal cancer patients have radical surgery. But because the cancer is often discovered late, aggressive treatment is quite common, often a combination of surgery, radiotherapy and chemotherapy with cisplatin or with the monoclonal antibody cetuximab (Erbix).

Aggressive radiotherapy is often given as a primary treatment or following surgery. Short-term problems usually subside after the treatment is finished, but in 4–5% of cases radiotherapy to the neck or mouth results in severe (stage 3 or 4) late

complications, drastically reducing quality of life. Problems include pain, loss of ability to taste food, deafness, fistulae in the mouth, problems with breathing or swallowing and bone necrosis.

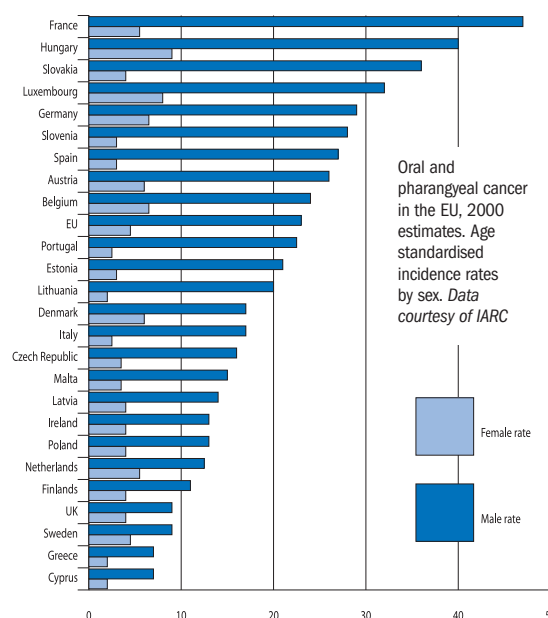
The US National Cancer Institute estimates that suicides amongst cancer patients may be two to ten times more common than in the general population and are probably underestimated. Given the impact of head and neck cancer on some of the most basic aspects of being human – speech, swallowing, facial expression – it is perhaps not surprising that the rate of suicide is particularly high in people with this type of cancer. According to Bill Lydiatt, associate professor of head and neck surgery at Nebraska University, patients with head and neck cancer make up only 2–3% of all cancer patients, but 19% of hospital cancer patient suicides.

HEAD AND NECK CANCER

Oral and pharyngeal cancer is the sixth most common cancer worldwide, and in Europe has poorer survival rates than for breast cancer, cervical cancer or skin melanoma, with a mortality rate of about 40%. Cancer can occur in the mouth, tongue, lips, throat, salivary glands, pharynx, larynx, sinus, and other sites. About 90% of head and neck cancers are squamous cell carcinomas.

Worldwide, more than 400,000 new cases of oral and pharyngeal cancer are diagnosed each year, two-thirds of them in developing countries. There are about 66,650 new oral cancer cases in European Union (EU) countries each year and a total of 100,000 cases of head and neck cancer. Incidence rates in Europe vary widely, with France and Hungary topping the league. Tobacco and alcohol are both strong risk factors.

Sources: IARC. GLOBOCAN 2002; Mouth Cancer Foundation; Cancer Research UK



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TECHNOLOGY IS IMPROVING

Jacques Bernier, head of radiation oncology at the Genolier clinic in Switzerland, says that improving technology and more precisely targeted radiation will offer substantial improvements over the next 5–10 years. The more accurately irradiation can be targeted on the tumour, the less the damage to surrounding tissue. However, the volume of tissue to be irradiated and dosage levels are critical factors in ‘consequential damage’ immediately after radiotherapy or even two or three years after treatment.

“One example is when you have a big tumour and you are rather aggressive in terms of radiation volume or dose. Obviously the tumour disappears, but in some cases you can be left with long-term damage to the mucosa, which practically never heals. If you are obliged to irradiate the whole oropharynx or the oral cavity you will face many more problems than with small fields – that is for sure.”

Radiation dosage is also important, especially in accelerated fractionation where high doses are given in a shorter time. “With conventional techniques for irradiation, anything in excess of 75 Gy is more likely to cause bone necrosis, teeth prob-

lems and other long-term effects.” Chemotherapy alongside radiotherapy is another potential cause of severe effects, although there are not yet enough data to be sure.

“Sometimes there is a trade-off between cure and complications that you have to discuss with your patient. For instance, if the patient is not keen on very mutilating surgery, then we propose a more conservative treatment.”

Bernier says that multidisciplinary follow-up care has improved. “When I started my career 20 or 25 years ago, I would say that most of the discussion was directed towards cure, and now half of the time it is dedicated to cure and the other half to quality of life. There is a lot of progress in terms of reconstructive surgery and microsurgery. If you have mandibular bone necrosis there are now wonderful surgical processes to reconstruct the bone.”

Vinod Joshi specialises in restorative dentistry for cancer patients in the north of England. In 2002 he set up a mouth cancer awareness website, and in 2004 this became the basis of the Mouth Cancer Foundation, which provides a forum for people from all over the world.

AWARENESS IS POOR

He says that there is a lack of awareness on the part of public and professionals about the scale of the problems. "Breast cancer has a lot of vocal groups and examples of famous women like Kylie Minogue. Mouth cancers tend to get lost and don't have a voice. A lot of these patients suffer more because they don't have the energy to be proactive, because they have difficulties with eating, with speech, and with fatigue and depression and they find it difficult to socialise. The side-effects of the treatment that keep you alive are ever present."

Joshi offers a range of reconstruction treatments in two NHS hospitals in the UK. In one, he sees patients before their cancer treatment to assess what prosthetics and reconstruction they might need afterwards. At the other hospital he sees patients only if the surgeon decides they need follow-up care after surgery. Teeth that are in poor shape are removed before radiotherapy begins, as there can be problems in doing this after the bone has been damaged by radiotherapy. He also fits dentures and prosthetics aids.

"If you have surgery to your tongue, you may have difficulty in swallowing if your tongue cannot reach to push the food backwards against the roof of the mouth. I can make them a plate to lower the roof so the tongue can make contact and push the food back. There may also be an opening between palate and nose we need to block off."

The Mouth Cancer Foundation's award-winning website (www.mouthcancerfoundation.org) contains human stories from the UK and around the world. Most message board members are grateful to be alive. But they also detail years of pain, disability and indignity.

'ILT' was treated with radiation therapy for tumour on the tongue thirty years ago. After six months he was clear of cancer, but began to suffer increasing pain and discomfort in his jaw, through spreading osteonecrosis. Surgeons decided to cut away the affected bone and replace it with a bone transplant from his hip. He regards the three months he spent in hospital as "the most traumatic part of my life".



The first operation was to remove dead bone. Two attempts were then made to transplant skin from his forehead to provide a base for a bone transplant in his jaw (the hair on this skin continued to grow in its new home). Replacement bone was then taken from the top of his hip bone. A framework of stainless steel rods and pins was screwed into his head and what was left of his jaw to hold the bone transplant in place until it took. During this time he was fed through a tube.

"I lost count of the number of times I had to visit the operating theatre. One nursing sister told me at one time she thought it was twenty-eight. At that time we were winning, so it seemed worthwhile. It had been explained to me that I would be rather badly scarred, particularly on my forehead, where the skin flaps were taken from, and also that I would be toothless for some time until the transplant had completely healed.

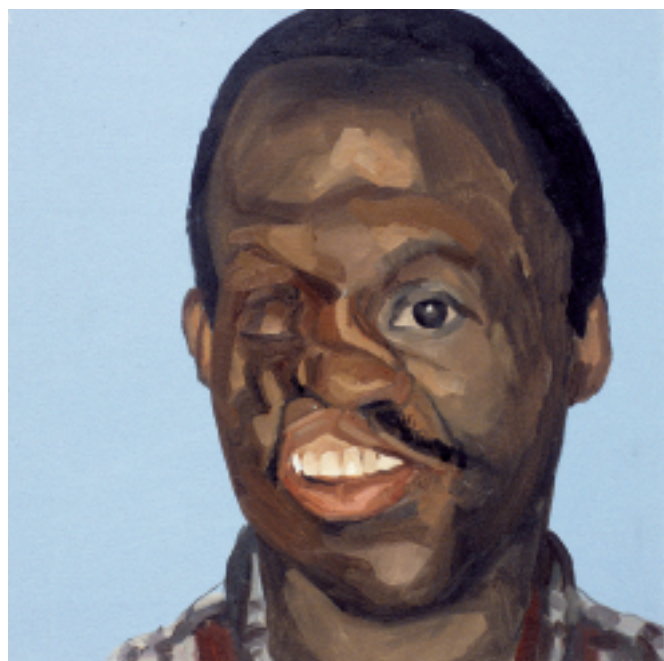
Today, with dentures he describes as "reasonably serviceable and cosmetically brilliant", he has some success with chewing food, but still a lot of difficulty in swallowing. For him, the struggle has been worth it. "I consider myself extremely lucky to be writing this and enjoying my good health as I approach my 78th birthday."

Project manager Raphael Stipic was diagnosed with cancer of the tonsil in August 2003 at the age of 44. He had ear and jaw pain for two to three years as a result of radiation damage.

"There have been times that I have been difficult, disrespectful to family members and argumentative. If I can give any advice it is to find a 'buddy' to support you through the difficult times and an outlet to express your feelings other than your nearest and dearest. I would have been absolutely evil and extremely depressed if I was on my own.

"I now understand when people say radiotherapy is damaging, although you have little choice other than to have the treatment. It's still worth all the initial pain and discomfort to ... ultimately extend your life."

At the age of 32, Vicki Lynn from Las Vegas, USA, had a ten-hour operation to remove almost half of her tongue, some of the floor of the mouth, and the lymph



nodes on the right side of her neck. Twice since then the cancer has returned, treated with radiation implants and further surgery.

Vicki says, "This neck dissection is one tough ordeal. It should never be taken lightly. The time to talk is before the surgery, because after it you will not be able to talk. Not for a long, long time. I am now in speech therapy ... it will be even harder for me to learn how to swallow again. The lips move fine. But since 80% of my tongue is gone, I cannot make all the sounds. I saw the doctor watching me struggle just to say the sentence 'I am coming home'. I wanted to die. Right then, right there." She doesn't think she could take another round of treatment. "I really feel that I am done with all this; I am so tired and worn."

Although there are a lot of positive comments on the web pages, there is also something close to despair.

David had part of the floor of his mouth removed in 2001, with a skin graft to cover the hole and a bilateral neck dissection, followed by radiotherapy. He has trouble making himself understood and even changed his name to Paul, as he found it easier to say. More than five years later, he still has problems with eating, being heard and being treated as a person. "Because I look a bit different, they presume I am either deaf, dumb or brain dead! This

"They presume I am deaf, dumb or brain dead!
And NO! I do not get used to being treated this way"

happens to me on a daily basis, and NO! I do not get used to being treated this way. It is a reminder all the time of what I am trying to live with."

Some of the anguish is inevitable, since only aggressive treatment will save their lives. But Christine Piff of *Let's Face It* would like to see more done to support patients by providing head and neck wards in hospitals, nurses experienced in caring for people with facial disfigurement and a counsellor to support them. She would also like to see groups like hers attached to every hospital where patients are treated.

TOO LITTLE SUPPORT

Vinod Joshi also believes more could be done. "At the moment, the only real support these patients get after treatment is follow-up in the hospital to make sure that they haven't got a cancer coming back. There isn't very much support to assist them in getting back to work and in financial support. Nothing to give them a circle in which they can form a community to support one another and get away from social isolation."

In the UK, the National Clinical Audit Support Programme, supported by the British Association of Head and Neck Oncologists (BAHNO), recently produced its second report on head and neck cancer, which collected information on more than 1,400 patients in England and Wales. This called for much better data collection for this group of patients.

It concluded: "The treatment and care of cancer patients could be improved if more was done to submit records systematically. ... Some important aspects of caring for patients, such as dental assessment, speech and language therapy, dietetics and palliative care could not be assessed through the audit owing to an absence of data."