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Head & Neck Newsletter

About this Newsletter

By Lisa Sanday and Edna Salt

Welcome to the 12th issue of
the Head and Neck Newsletter!



The Richard Dimpleby Cancer Information and Support Service (**RDCISS**) produce this newsletter twice a year. It is circulated via our mailing list, and to the clinics and wards at Guy's and St. Thomas' Hospitals.

The Newsletter aims:

- To let you have your say about your experiences of head and neck cancer.
- To provide a way for you to voice issues that matter to you.

Thank you for your ideas for this issue of the Newsletter. If you have any thoughts for the next edition or you would like your name to be added to or removed from the mailing list please contact:

Lisa Sanday
Cancer Information Officer
RDCISS
2nd Floor, Lambeth Wing
St. Thomas' Hospital
London SE1 7EH
☎ 020 7960 5682

The Richard Dimpleby Cancer Information and Support Service

This service offers:

- Information about cancer.
- Psychological support.
- Day care.
- Complementary therapies.
- Benefits advice.

RDCISS is available for patients, their families and friends, who have cancer related issues who attend Guy's, King's and St. Thomas' Cancer Centre. The service is available at both Guy's and St. Thomas' sites.

RDCISS is also the venue for:

- 'Look Good Feel Better'.
- Patient Liaison Group.

Please contact **RDCISS** for more information about the services provided.

☎ 020 7960 5682

Guise and Dolls Support Group

By Jean Meadows

Hi! I'm Jean. I run the monthly Guise and Dolls Support Group with Caroline Lees. The group meets from 1pm to 3pm on the third Monday of every month on Patience Ward, 15th Floor, Guy's Tower, Guy's Hospital. The next two meetings are:

21st October

18th November

I will tell you about two particular meetings that were very popular with the group. These meetings generated a great deal of discussion and debate from the members.

The first was in April, when Bernadette Castle from "Changing Faces" came to talk to us. Bernadette told us about the workshops Changing Faces do to help people with faces that look different either through surgery, or through accidents such as burns.

Bernadette chose to focus and discuss with us the problems specific to those of our group:

- Other people's reactions.
- Eating difficulties.
- Speech problems following surgery.

Bernadette used a **SCARED** exercise to help the group talk about their feelings about how they look or sound. She asked the group to give examples of reactions that use the letters of **SCARED**, starting with what they might think and feel and what someone meeting them might think and feel.

For example:

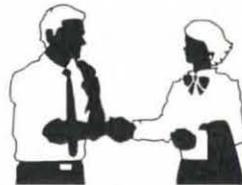
After head and neck surgery,

a person may:



- S** be self-conscious or shy
- C** feel conspicuous
- A** feel alone, angry, anxious
- R** feel rejected
- E** feel embarrassed
- D** feel different, depressed

Someone who meets this person may:



- S** stare, sympathy, shock
- C** be curious
- A** assume, feel anxious
- R** recoil, feel repelled
- E** feel embarrassed, evade
- D** dread it, feel depressed

Bernadette encouraged the group to describe situations where these feelings happened. She talked about how we can learn new ways of how to behave before the **SCARED** process has a chance to start.

This involves the **REACHOUT** process, which aims for you to make the first move. It advises you to impress your personality on others before they have a chance to make a judgement about you.

R REASSURANCE

Reassure people that they have no reason to feel uncertain. Hold you head up, maintain eye contact and smile.

E EFFORT

Match the energy and effort of other people, if you are going to appear interesting. Enthusiasm will help make people listen to what you are saying.

A ASSERTIVENESS

Confident eye contact, clear firm voice, and a confident posture can give the image of a positive person. People will respond in the same way.

C COURAGE

Build on every small success and you will feel confident in new situations.

H HUMOUR

An effective way of reducing tension and making people feel relaxed.

O OVER THERE!

Commenting on something the other person is doing or wearing will shift the focus of attention away from you.

U UNDERSTANDING

Other people may not know how to behave in this situation. You can help them by giving the message that you are not embarrassed or concerned.

T TRY AGAIN

Don't be discouraged! Learn from what didn't work and try something else, until it works.

If you would like to find out more about these workshops or about 'Changing Faces' please contact Bernadette at:

Changing Faces
1 & 2 Junction Mews
London WC2 1AP
☎ 020 7706 4232

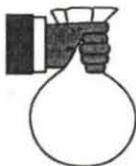
Internet: www.changingfaces.co.uk

E-mail: info@changingfaces.co.uk

In August, the **Benefits Advisor** Louis Nichols, visited Guise and Dolls Support Group.

Louis and his colleague Janet hold fortnightly Benefits Clinics at Guy's and St. Thomas' Hospital sites.

The clinics were set up by RDCISS early in 2002. The aim was to enable patients attending Guy's, King's and St. Thomas' Cancer Centre, to obtain financial information from Benefits Advisors.



Guy's Hospital

PLACE: RDCISS Info Room
Medical Oncology
3rd Floor
Thomas Guy House

TIME: 10:30 – 12:30

DATES: September 30th
October 21st
November 4th & 18th



St. Thomas' Hospital

PLACE: Clinical Oncology
Lower Ground Floor
Lambeth Wing

TIME: 10:30 – 12:30

DATES: October 3rd & 17th & 31st
November 14th & 28th

Louis informed the group about some of the available benefits. He also talked about the apparent gaps in the system.

The group discussed benefits and problems that people with head and neck cancer can have. This includes problems with prescription charges, dental and optician costs.

The group discussed lobbying MPs to change the system. It was thought that a petition from the group would not be helpful, but that each person should write a letter to their MP.

Clive, one of the group members, designed draft letters to give us an idea of how to proceed. The group members were keen to write to their MP. Perhaps you may want to do the same.

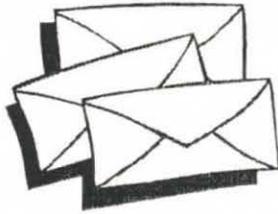


How to write to your MP

- Find out who your MP is via local library or Internet.
- Keep the letter short and simple.
- Avoid party political comments.

The following letters are for guidance only, delete or change details to suit you, or rewrite it in your own words. The letters are examples of some of the issues discussed in our recent group meetings. Choose your own issue to write about. Start with a few details about yourself and then a paragraph to describe your issue.

LETTER EXAMPLE ONE



Dear Sir,

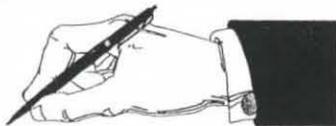
I am X years old, and had surgery to my head and neck X years ago. This has left me with speech difficulties, and I am not able to work. I have lived in this area X years / all my life.

I am writing to you to inform you of the expense of multiple prescriptions that certain people have following surgery. Each prescription costs around £6, and ten or more different drugs maybe required. This can be costly. Please could you ensure that the appropriate government minister is made aware of this problem.

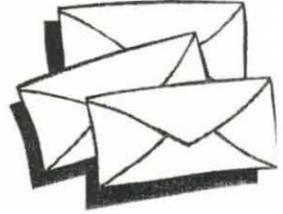
I would like to explain my difficulties to you in person. Please could you let me know when we could arrange to meet.

Yours faithfully,

X



LETTER EXAMPLE TWO



Dear Sir,

I am X years old, and had surgery to my head and neck X years ago. This has left me with speech difficulties, and I am not able to work. I have lived in this area X years/ all my life.

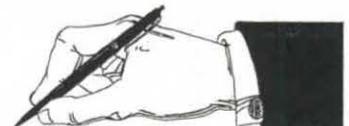
I am writing to you to explain the difficulty I faced recently in identifying the benefits that I could claim. I have been claiming X benefit for some years, and only recently found out that I could also claim X. Even this does not help me much, as I have to pay the first £200 of any dental treatment, and the first £130 for my glasses. As I do not have much income this means that I still am not able to afford the glasses/dental treatment I need. I have no idea what other benefits might help me, as there are so many.

Perhaps you could ensure that the appropriate government minister is made aware of this situation, and urge them to make things simpler.

I would like to explain my difficulties to you in person. Please could you let me know when we could arrange to meet.

Yours faithfully,

X



Edna Salt suggested a couple of poems she found in the Daily Mail. She thought that they were amusing as they were cynical about the NHS and the government.

*I wondered lonely as a cloud
Thro' corridors long and bright
And chanced into a coffee room
And beheld an awesome sight.*

*A tree pulped, bleached and printed
A package hard to shift
Four and twenty virgin copies of 'The Gift'.*

*Each one packed with writings
Deep, obscure, obtuse
And like a chocolate fireguard,
It ain't much bloody use.*

*But speak not like the cynic
Let your spirits be uplifted
We're the Blairite Brummie Army
Or the NHS, 'The Gifted'.*

*So, thank you Health Authority
You've caused us all a laff
Buying books of poetry,
Instead of hiring staff.*

*As we titter on our way
You're wisdom we'll admire
While, understaffed and overworked
We sink further in he mire.*

*What is this thing called progress?
Where is it leading to?
Nothing's getting better for the likes of me and you.*

*Education once was fine,
At least it was when I had mine.
All police were people you could trust
Upholding all we know as just.*

*Hospitals were clean, spotless places
Thanks to Matron's airs and graces.
And you could rely on British Rail
Its timetable would seldom fail.*

*What if you wrote to friends away?
Well, they could read it the next day.
We had this thing called first class mail
Now post goes slower than a snail.*

*Progress has made one thing for sure,
Nothing is better than before!*

*Grass was something dad would mow,
Now they are selling all they grow.
The only time I had cocaine
Was at the dentist's for the pain.*

*But now the young, some older too
Are drowning in a hazy hue.
We watch them slipping away
Wrecking their future as they play.*

*Progress is something to reverse
It is the nations greatest curse.*

R.N. Franklin
Birmingham



Linda Collyer
St. Helen's, IOW



Gillian Turner writes a letter to her four-year-old grandson about her experiences on Patience Ward, at Guy's Hospital.

"I'm having an amazing adventure. Outside my window there's an old castle, a bridge that lifts and splits in the middle to let big ships through, a big river with boats, a busy railway station and everywhere tall cranes building skyscrapers. At night it's like a fairyland with all the lights and there have been fireworks! There is always something going on, something to see.



My adventure started because I needed part of my tongue and my neck glands removed because of a cancer (this was done while I was asleep by the way). When I woke there was the mark of Zorro in the middle of my forehead. It was where the breathing tube was fixed, but it's gone now so you won't see it.

Guess how I had my meals? I could talk and sing and even clean my teeth while eating! How? Because the food went down a tube through my nose directly into my stomach. However the tube got taken away, and now, like you, I mustn't talk with my mouth full or put too much in!



You would have loved the metal tracks on my neck. Like a toy railway except the track didn't link up, and there were only sleepers and no lines. But they've gone too – sorry! But you can see the scar where they were – my souvenir trophy!

Nat – the speech therapist is teaching me to – guess what – stick out my tongue! It's to help my speech. We'll have a competition again. You used to win but now I think I'm in with a chance. And Nat has given me a story about Arthur Rat, which I think you'll enjoy – but I have to read it for practice.

By the way, we don't call it 'teeth cleaning' any longer. It's 'oral hygiene', and it's very colourful. First there was clear hydrogen peroxide, which foamed into white froth. Then the pinky red mouthwash that bubbled up like candyfloss, and finally a dark blue dye to check for leaks between my mouth and neck. It looked like the Union Jack around my mouth. There were no leaks, so my neck never went blue. I was sort of sorry as it would have looked so interesting – I mean cool!

And now for the best bit. Star Wars and my mask. First there was the face pack – the best, thickest, warmest, wettest face pack I'd ever had – and all for free. It was white plaster – like your brother had when he broke his arm. They used this to make my Darth Vader mask – except that it's transparent. You can have it when I come home. Perhaps we can paint it to make it look, more real.



The mask keeps my head still so the rays can zap any stray cancer cells in my mouth. But the rays are invisible – not like the beams from the Star Wars swords! That would have been fun! When I come home I'll have a red face and a bald patch or two. You can laugh! But it won't last!



And finally I must tell you about the angels. No wings, but some white robes, the odd one with long curls and a few with little hair. They come in all shapes, sizes, sexes and colours. They work day and night. They are everywhere – the ward, the theatre and the clinic. They are the **PATIENCE** team alias the **McGURK MARVELS**. They have looked after me, made me better and given me such a happy time. We'll come and see them together sometime.

Be good.

I'll be home soon."

"Saving Faces"

An exhibition at the National Portrait Gallery

By Caroline Lees



In May, I visited a fascinating exhibition of paintings by Mark Gilbert at the National Portrait Gallery. Mark is a portrait painter who worked with Ian Hutchinson (a Consultant in Oral and Maxillofacial Surgery at St. Bartholomew's and the Royal London Hospital). Mark was the artist in residence in the unit for a year, and the portraits were of some of the patients who had operations during that time. His paintings were of the patients both before and after their surgery. Some were of children with benign tumours, some of people who had severe facial injuries due to accidents, but those most of interest to me were of two patients who had surgery for head and neck cancers. One was a painting of a patient wearing his radiotherapy mask – this had been done at the patient's own request.

I visited the gallery twice. The first time, Mark was speaking with a group of school children, and on the second he gave a talk about the paintings and his experience of working in a hospital setting. The paintings were very large and the colours bright and bold. Mark told us how much the patients had wanted to take part in the project and had enjoyed the process of being painted. He had completed many more portraits than could be shown. All the sitters had been very keen that their own should be included in the exhibition.

Mark said how apprehensive he had been at the start of the project – wondering how the patients and staff would receive the idea. It seemed that he developed a special relationship with those taking part and it appeared that this helped them to feel accepted by society again. The patients with cancer were the only ones whose operation had left their faces more altered than prior to surgery. All the sitters were keen to have their portraits exhibited to help educate the public about the nature of facial disfigurement. I was particularly impressed by Mark's talk to the school children as it felt a positive step in explaining to them about how to accept people being different.

The exhibition was a celebration of different faces and it seemed appropriate that it was placed next to the Mario Testino photographs of glamorous personalities looking at their best. The exhibition is now on tour around the country.

Saving Faces was launched in June 2000 aims to fund research into all aspects of facial diseases affecting the mouth and face such as cancer, facial deformity, injuries and pain. It will also attempt to increase public awareness of oral cancer and other facial diseases by widespread publication of this research.

Saving Faces

P.O. Box 25383

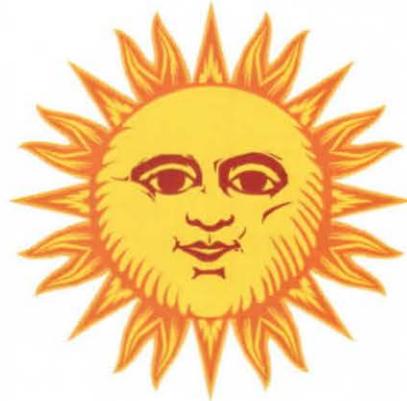
London NW5 2FL

☎ 020 7485 5945

E-mail: savingfaces@mail.com

And finally.....

“Let’s Face It” Garden Party



Hello friends,

On 17th August, on a sunny and hot day, myself, Brian, Jean and Audrey from the Guise and Dolls Group met at Guy’s Hospital. We set off for the annual garden party in Yately, Hampshire, where we saw some of our old friends and also some new ones. On the whole as for every year everybody had a nice time!

K. Sewell

Not many shopping days until Christmas now! A good time to remind you of our Christmas party!

Guise and Dolls Christmas party is on December 16th.



Dates for **2003** for Guise and Dolls Support Group:

- January 20th
 - February 17th
 - March 17th
 - April 21st
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