

# SCN Partnership Group

SEPTEMBER  
NEWSLETTER 2011

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Further newsletter copies can be downloaded from the website

[www.sussexcancer.nhs.uk](http://www.sussexcancer.nhs.uk)

*Contributions from Members are always welcome; please send information to the Network Office.*

If you would like a full copy of any of the information obtained in this Newsletter, please contact either:

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or phone: 01273 574801  
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Sussex Cancer Network  
Brighton & Hove City PCT  
Lanchester House, Trafalgar  
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part of the NHS Sussex Cancer Network

# Newsletter

The Partnership Group  
will meet on

**Saturday**  
**10th September**  
**2011**

at

**36-38 Friars Walk**  
**Lewes, BN7 2PB**  
**10am to 1.30pm**

our speaker will be

**Anne Catt**

Service Improvement Manager

**Service Improvement**  
**Progress & NAEDI**

**All are welcome**

for more information

**Tel: 01273 574801**

**or 0800 561 0025**

**[www.sussexcancer.nhs.uk](http://www.sussexcancer.nhs.uk)**

# Partnership Group Reports

## Brief Summary of the SCN Partnership Group meeting held on 9th July 2011

- ◆ There was a presentation by **Shaun Innes** (Head of Transport Brighton & Sussex University Hospital NHS Trust) about the Patient Transport Service across Sussex. Questions and discussions were held around; options for patient transport / long waits for transport / areas covered in Sussex / eligibility of applying for contracts / eligibility criteria of cancer patients and carers / flexibility of service / patient consortiums.
- ◆ **Patient Prescriptions** – CH updated the group on the progress of patient prescriptions –
  - ⇒ Eden French (Macmillan Patient Information Project Manager) is currently attending all the site specific SCN tumour groups to flag the prescriptions and would like support from patient reps on the tumour groups and other members of the MDTs, to make sure they are all aware.
  - ⇒ Post of project worker for information prescriptions is moving forward;
  - ⇒ Need to make sure information is also available in primary care / libraries etc.
  - ⇒ Revised SCN website – nearly ready; will require patient feedback on new style.
- ◆ **Peer Review** – User Involvement Measures  
CH reported the new measures require the Partnership Group and tumour groups to work together to agree standards of care for patient-centred care, supportive care, transitional care and self management; following which a baseline assessment and a needs assessment will need to be completed.
- ◆ **SCN Partnership Group PPI Strategy**  
In light of the new Peer Review measures, the PPI Strategy will need to be reviewed – but can not be completed until the gap analysis is complete. Discussions were held around what has been achieved and where we are now and where we are going. Need to make sure the group links into Commissioning Health & Well Being Board – MB will look at how the Partnership Group links into this.
- ◆ **Updates from Macmillan Nurse Director**
  - > Development of a DVD for patients around Neutropenic Sepsis, a plea was made to the group for offers to review the DVD. > MV & CH attending NCAT pilot on GP commissioning on 13<sup>th</sup> July. > Future structure of the Sussex Cancer Network still going out for staff consultation – expected timeframe is in the Autumn.
- ◆ **Partnership Group / Brighton University DVD**  
CH confirmed permission from all members who took part in the filming has been received for the DVD to be widely distributed including via YouTube; Chapters of the DVD have been seen by numerous SCN groups including, SCN Commissioning Group / Lead Managers Group / Lead Cancer Nurses / & Primary Care Cancer Lead Group; CH highlighted one potential issue around PSA testing – which may cause some questions an information sheet with the pros and cons of PSA testing should accompany the DVD when it is sent out and that a link to the appropriate section of [www.healthtalkonline.org](http://www.healthtalkonline.org) should be highlighted.

*Mandy Lynch*

## Summary of the Sussex Macmillan Cancer Support Centre meeting held 29th July 2011

Planning application now in. A query regarding parking whilst the building is being constructed has been resolved.

Focus Groups will be set up by Geoff Brown, the Project Manager, to explore the needs of patients using the building. It is hoped details will go out shortly.

The Appeal has raised £1.33 million. Direct Mailing has now gone out to all supporters.

A Gala Dinner is to be held at the Brighton & Hove Albion Amex Stadium on the 2<sup>nd</sup> September 2011 with proceeds to go to the fund.

*Margaret Ticehurst*

## Members reports & news

I booked up to have my wig cut. This is now a charity – ‘Mynewhair.org’ and has full Dept. of Health backing. It helps with alopecia and hair loss related to chemo or any other reason. You book an appointment and you can have a wig cut etc. FREE and also book up for after advice about re-growth strength and styles etc. I think it is a good service to promote and a nice change from all the medical work we look at. This is the kind of thing that helps one deal with the reality of the cancer treatment. I also managed to get a free haircut from a trainee - it is the best short cut!! (Shame it wont last).



I went to my breast support group and a presentation there was about a new acute oncology nurse Lisa Barrott at RSCH. This is a Mon–Fri, 9-5 service and gives back-up for cancer patients at A&E. The idea is for a more holistic coordinated approach to prevent duplication and unnecessary tests.

Helen O’Gorman

### 3 interesting meetings in 8 days

**On 14th July**, at the invitation of Debbie Hatfield, the chair, I attended a meeting of the Service Users & Carers Strategy Group of the University of Brighton School of Nursing & Midwifery. The group plans and manages the involvement of service users and carers in the school's courses. It was very interesting to learn about the considerable extent and range of that involvement up to now and to be invited to contribute to its ongoing development.

**On 20th July**, along with three other members of the group, I attended the public question and answer session and the public board meeting of the National Institute for Health and Clinical Excellence (NICE) in the impressive Audrey Emerton Building at the Royal Sussex Hospital. This was the board's annual general meeting. The question and answer session, preceded by a very interesting and informative presentation by the Chief Executive, Sir Andrew Dillon, was lively and covered a lot of ground, including the way in which NICE makes its often controversial decisions about the availability of new drugs. At the board meeting the public were invited to ask questions and make comments after each item on the agenda. NICE does not have an easy public image and it was good to see and hear the actual people involved and get a sense of their motivation.

**On 22nd July** I was back in the Audrey Emerton Building to meet first with Colin Twomey, Macmillan Team Leader in the Sussex Cancer Centre, to discuss the centre's application for Macmillan funding for a Lymphoma Clinical Nurse Specialist, and then with Jane Stach, a member of the group and a lead cancer nurse in the Cancer Centre, to discuss her plans for a leaflet for lymphoma patients at the centre. Both discussions were very interesting and I hope useful.

Peter Norris

# Partnership Group meeting dates for 2011

10th September <> 5th November

All meetings to be held on a Saturday  
10am to 1.30pm at 36-38 Friars Walk, Lewes

## **WANTED**

### **Reps on Groups**

The Partnership Group need more patients and carer representatives on some of the various groups and committees which form the Sussex Cancer Network.

If you are interested in becoming involved with one of the following groups, **please contact Caroline Huff for further details on 01273 574801 or 0800 561 0025**

#### ***Tumour Groups***

Chemotherapy <> Haematology <> Upper GI

#### ***Cancer Action Group***

Central Sussex

#### ***South East Coast***

New Cancer Drugs & Therapeutics Evaluation Committee

# Patient Support Group News

## OESOPHAGEAL PATIENTS' ASSOCIATION South Coast Branch

Former Patients helping New Patients  
Cancer Support – Charity No 1062461.



Meeting at: The White Horse Hotel Function Room, Rottingdean,  
Brighton, BN2 7HR

**Wednesday 12<sup>th</sup> October 2011 2pm – 4pm**  
**Speaker: Holly Taylor, Nutritional Therapist**

We welcome anyone who has undergone an Oesophagectomy or Gastrectomy and those who have been diagnosed with Upper GI cancer who are seeking information from former patients about life after such surgery. Partner/carer also welcome to attend. Informal and friendly, refreshments available and parking nearby.

Contact: Verena Smith - Coordinator/Secretary.  
Mobile: 07964 925 494 (before 9pm please)  
(OPA National Helpline: 0121 704 9860. [www.opa.org.uk](http://www.opa.org.uk))

### National Oesophago-Gastric Cancer Awareness Month

Verena Smith and several patient members and their partners/carers of our Support Group had attended and helped Claire Elliott, Macmillan CNS with the AUGIS awareness event which took place in the reception of the Audrey Emerton Building on 5th July.

This event was to draw attention to Upper GI cancers and to encourage members of the public to be aware of possible symptoms and seek early advice from their GP.



## RAISING PROSTATE CANCER AWARENESS

PCaSO

ALL MEN OF AROUND 45 TO 79  
ARE INVITED TO A

### FREE PSA BLOOD TEST

AND A TALK GIVEN BY  
DAVID BAXTER-SMITH *Consultant Urologist*

on **SATURDAY 8th October 2011 - 2pm to 4pm**  
at the **BRIGHTELM CHURCH & COMMUNITY CENTRE**  
North Road, Brighton BN1 1YD



**For more information please call**

**01273 387371 or 07831 156071/2**

# Macmillan News

## Cancer Voices, Self Help & Support Groups in Sussex Summer 2011

Greetings! My name is Jill Corbyn and I am the new Macmillan Involvement Co-ordinator working in Surrey, Sussex and Kent. It's my job to work with Cancer Voices, enable Self Help and Support Groups and to help people affected by cancer to influence the future of cancer services. I have a lot of ground to cover, but in time I hope to meet all of you – so if you see me out and about please do come and say hello!

If you want to find out more about Macmillan grants to support or help you set up a group, or about volunteering opportunities, then please get in touch. I'd love to hear from you – [jcorbyn@macmillan.org.uk](mailto:jcorbyn@macmillan.org.uk)

I hope that the Our News newsletter will provide regular helpful information about services and opportunities in your area.

## Learn Zone

Did you know that Macmillan Cancer Support has a range of helpful online courses that are free to access once you have registered. These include: Getting involved  
Helping yourself (self management)  
Supporting Others

If you volunteer with Macmillan, there are also many more courses available to you. These include: > Introduction to Cancer > Relaxation Corner > Family Matters  
To find out more go to <http://learnzone.macmillan.org.uk>

## Cancer Voice Opportunities

There are lots of opportunities listed on the Opportunities Exchange Website and anybody can register. Opportunities include reviewing books, taking part in patient surveys and focus groups, giving an interview to the media and attending conferences and events. If you're not a Cancer Voice but would like to be, then get in touch with me and I'll send you a form, or log onto the Macmillan Website at: <http://www.macmillan.org.uk/GetInvolved/CancerVoices/CancerVoices.aspx>

## Cancer Voices Conference

The Gatwick Hilton Hotel is hosting the Cancer Voices Conference  
on 14th and 15th October 2011

**Accommodation and travel costs are paid by Macmillan**, and it's a great opportunity to meet other Cancer Voices and hear about some of the fantastic work that is going on across the country.

Put the dates in your diary – more information to follow.

# Macmillan News

## World's Biggest Coffee Morning



**Put a smile on your mug!** Be part of Macmillan's **World's Biggest Coffee Morning**. Get together with friends, family and colleagues on **Friday 30 September** and raise some money for people affected by cancer.

Supporters and needed across **Surrey, Sussex and Kent** to host Macmillan's World's Biggest Coffee Morning. We also need help to tell other people about the event and to make sure that our hosts are well supported. Get in touch or look on the Macmillan Cancer Support website to find out more. <http://coffee.macmillan.org.uk/Home.aspx>

### Opportunities In Sussex

#### Befriending Volunteers wanted in Hastings area

A group of volunteers in the Hastings area is developing a befriending service to support people in their community who are affected by cancer. The group is looking for more volunteers to support their great work. To hear more about this project and to find out how you can get involved in the Hastings area or to set up a new group, give me a ring on 07703 681 206 or email [jcorbyn@macmillan.org.uk](mailto:jcorbyn@macmillan.org.uk).

#### Welfare Benefit Adviser Volunteers Wanted, The Martlets Hospice

As a Volunteer Welfare Benefit Adviser you would support clients in coping with the 'cost of cancer', advising and offering support in obtaining benefits for themselves and their families. For more information contact Lisa on 01273 273400 ext 417 or email [volunteering@themartletshospice.co.uk](mailto:volunteering@themartletshospice.co.uk)

## It's official, The Splash of Green Charity Ball - 2012

in aid of **Macmillan** Cancer Support's new Information & Support Centre now booked

**Same place:** The Grand Hotel, Brighton. **Same band:** The Blunter Brothers

**Same month:** 31st March 2012 **Same price:** £50 per ticket

[http://www.macmillan.org.uk/Fundraising/Inyourarea/England/Sussex/SussexAppeal/Local\\_news/SplashofGreenBall.aspx](http://www.macmillan.org.uk/Fundraising/Inyourarea/England/Sussex/SussexAppeal/Local_news/SplashofGreenBall.aspx)

This means, that another excellent evening will take place, raising even more money for **Macmillan Cancer Support**.

Tables of 10 are encouraged, but not essential. You can book directly online via:

<http://www.freewebstore.org/splash-of-green-charity-ball/index.aspx?pageid=478297>

Send a cheque; or BACS transfer. We look forward to hearing from you.

**Della, Bobbie, Tracey & Faye**

**Splash of Green - Macmillan Fundraising Group**

[www.dellaferri.com](http://www.dellaferri.com) t: 01444 448 138 m: 0777 374 8011

e: [dellaferri@uwclub.net](mailto:dellaferri@uwclub.net)

## The Benefits of Being Positive by Brian Campion

When last year, I was told I had prostate cancer, it came as quite a shock, even though I had been half expecting it, but never the less, I was really hoping to be proved wrong. After the initial shock sunk in, my main worry now was how to break it to my wife, as she's always been a bit of a worrier. As the weeks went by, my PSA, which was very high initially at 70, tumbled right down to 2.9, thanks to the hormone treatment (Zolodex) I was receiving, and after an MRI and CT scan showed the cancer had luckily not spread beyond the prostate, we were both feeling much relieved. My wife commented to me, "You don't seem at all worried about your condition", to which I replied, "It won't do me or you, any good to worry about it. I can't change the fact I've got it, and it won't make it any better by worrying about it, in fact I believe it will only make it worse. I have just got to accept it, and concentrate on beating it, with all the help I can get".

My father in Canada told me he was diagnosed with the same complaint way back in 1994 and that he was still cancer free. The more information I received, the more positive I became. After a course of radiotherapy at Brighton Cancer Clinic I feel very positive about the future and sincerely believe I've beaten it, even though it will be some time before I will know for sure.

I have always believed in a positive attitude and over the years, many things have increased this belief. We have all heard of drug trials where a percentage of people who have been given the placebo, report an improvement in their condition. My own view is that if you have faith in your treatment (and I don't necessarily mean religious faith) you are much more likely to improve. I have a theory that a positive mental attitude will trigger a part of the brain into starting, or even increasing the body's natural immune defence system. Most of the people that I know who have survived life threatening illnesses are all people who've had a positive attitude. My family have all been very supportive from day one, my three wonderful grandchildren especially, and this has been a great help. I know from experience, it's a big shock to the system to be told you have a serious medical condition but since finishing my treatment, I have met several other people who like me, have the same complaint, and I have encouraged them to adopt the same attitude as I've done, and I sincerely hope this will help them as much as it has helped me.

## Sharing Experiences with Medical Students

I run one hour seminars throughout the year for 4<sup>th</sup> year medical students, organised by Kate Lankester, Honorary Senior Lecturer at the Brighton Medical School, as part of their oncology training. I use my own photographs in a 12 minute slide show followed by a discussion of students' feelings and thoughts about these slides. The photographs were taken by myself on an autobiographical photo-shoot in the actual hospitals where I had my treatment. They simulate my own experience of what it felt like lying on a trolley going to an operating theatre, being in a radiotherapy room and having MRI scans.

The discussions generated by the slide show cover a range of students' thoughts and feelings which show their own awareness that the patient can undergo a variety of experiences such as: aloneness, isolation, loneliness, feeling scared and trapped, claustrophobia, disengagement, liberation, fear of dying, the realization that for a patient in a hospital environment people and objects can become very threatening and can trigger negative memories for them, and the importance of health care professionals talking with patients in calm, friendly and relaxed way.

In addition to the slide show, we use some of my written experiences from my document, "*Little Things Can Cause Larger Consequences*", which is available for students on the Medical School's intranet. This document is a collection of my own written accounts from my journal of some of the experiences I had with health care professionals whilst receiving treatment and care for my cancer. These experiences had both positive or enabling outcomes or negative disabling outcomes for me in the way I felt as a patient.

Students have indicated that they find these seminars enjoyable and that they give them a useful insight in what it actually feels like to be a patient. I am grateful for being given the opportunity by Kate Lankester and the Brighton Medical School for being able to personally contribute my experiences as a patient in a positive way.

Martin Brennan email: martbren@aol.com

## Do's and Don'ts of Chemo

I went and saw the DVD on Do's and Don'ts of Chemo on 11/8/11.

The Worthing Chemo Lead Nurse presented the DVD to a patient group for feedback.

- ⇒ **The DVD will be given to people across the SCN in Sussex at the Chemo information session which takes place before chemo starts**
- ⇒ **The DVD is a mix of patients and actors telling real patient stories about when things go wrong whilst on chemo treatment for cancer**
- ⇒ **The DVD sends the clear message 'do not ignore any symptoms post chemo**
- ⇒ **Advice is given about what to look for ie: increased temperature and/or feeling unwell**
- ⇒ **The DVD is strong in telling you what happens when you go to A&E with serious chemo problems**
- ⇒ **The HEAT card that chemo patients (Sussex) carry is well promoted in the film**

As an SCN rep I commented that the DVD is a useful addition to patient information and about the need for the chemo DVD to highlight that people may be alone and very ill and have the option to call an ambulance to help them manage crisis.

Helen O'Gorman

## SCN Management Update by Caroline Huff

- ◆ The plans are progressing for the **expansion of radiotherapy services to sites at Eastbourne and Worthing**. A Full Business Case is being developed for the Eastbourne site and planning permission requested. Discussions about timescales are underway in relation to the Worthing site ensuring the agreed timescales are met, alongside their need to build a new breast unit.
- ◆ Each Trust has responded with an action plan on addressing the issues which are blocking the age-extension for **bowel cancer screening**
- ◆ NHS Sussex has decided to postpone the procurement process of selecting one **level 3 and 4 (Bone Marrow Transplant) Centre for the SCN** until the publication of the revised peer review measures.
- ◆ The new **Sarcoma Diagnostic clinic** is up and running. This will enable patients with possible sarcoma to have their radiological investigations in Brighton, with referral on to the Royal Marsden Hospital if needed.
- ◆ WSHT are still gathering data, which will be reviewed to inform the decision on whether they should remain as part of 2 cancer networks or whether there is value of them being aligned to one only.
- ◆ In July Mike Vincent and I attended a National Cancer Action Team event of the **future of cancer commissioning**. It was a useful meeting with the SCN and Central South Coast Cancer Network Commissioners, GPs and patients. A collation of the findings from all the events will be developed by NCAT.
- ◆ Lesley Droney, Macmillan Lead Allied Health Professional is updating the **rehabilitation pathways** and developing a service specification (standards) for lymphoedema.
- ◆ We have been informed that the **raising awareness pilots for colorectal cancer** will be rolled out Nationally in January 2012.

# National News

## Launch of the National Cancer Patient Experience Survey 2011

Following the success of the 'National Cancer Patient Experience Survey 2010', the Secretary of State has committed to repeating the survey in 2011. This will be conducted in all NHS trusts offering adult acute in-patient cancer services. The survey will enable us to identify and build on progress that has already been made following the 2010 survey and help target efforts to continue to improve patients' experience of NHS cancer care.

## Survivorship PROMs survey pilot

The National Cancer Survivorship Initiative is piloting a 'Patient Reported Outcome Measures Survey' of cancer survivors in summer 2011 to understand the quality of life health outcomes reported by cancer patients.

The pilot survey is aimed at gaining a longitudinal picture of the impact of cancer and its treatment on quality of life for patients at various time points since diagnosis. A sample of adult patients with a primary diagnosis of breast, prostate, colorectal/ lower gastro intestinal cancer and Non-Hodgkins lymphoma will be included, based on patient data identified in selected relevant trusts working with the Thames, East of England, and West Midlands Cancer registries.

For more information about PROMS surveys visit: [Quality-health.co.uk](http://Quality-health.co.uk)

## Liberating the NHS: Greater Choice and Control

On 19 July 2011, the Department of Health (DH) published the Government's response to comments received on extending patient choice of provider (any qualified provider) and guidance for the NHS on 'Extending Patient Choice of Provider'. In this guidance, the DH identified diagnostic tests closer to home to support primary assessment of presenting systems as potential services for priority implementation. Also, DH is developing a further list of services to consider for patient choice of 'Any Qualified Provider' implementation in 2013/14. This will be subject to further engagement with patients, professionals and providers but may include: community chemotherapy services, including home chemotherapy.

For more information visit: [Liberating the NHS: Greater Choice and Control](#)

## Commissioning Cancer Services

One of the commitments in 'Improving Outcomes - a Strategy for Cancer' (2011) was to develop further the 'Cancer Commissioning Guidance'. On 25 July 2011 the Department of Health published 'Commissioning Cancer Services' as a transitional update to the Cancer Commissioning Guidance to support the commissioning of cancer services across the NHS. This update should be read in conjunction with the NHS Cancer Commissioning toolkit.

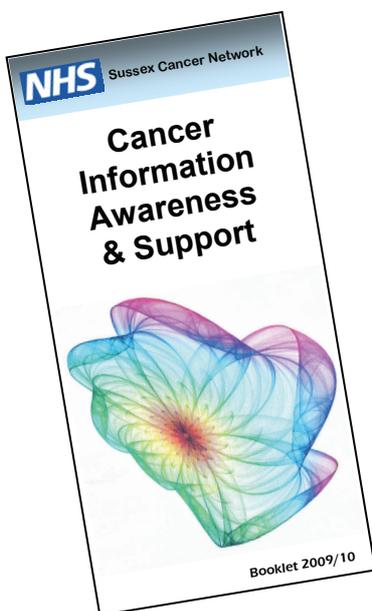
For more information visit: [Commissioning Cancer Services](#) and for the cancer commissioning toolkit: [NHS Commissioning Toolkit](#)

## Healthy Lives, Healthy People: Update and Way Forward

The Government has published a response to the Public Health White Paper consultation and NHS Listening Exercise. It reaffirms the Government's determination to create a more effective public health system and sets out progress to date. It covers the future of Cancer Registries, the National Cancer Intelligence Network and Cancer Screening; and it says that further consideration is being given to responsibility for early diagnosis of cancer. For more information visit: [Healthy Lives, Healthy People](#)

# The SCN Cancer Information Awareness & Support booklet has been distributed around the Sussex Cancer Network.

This 32 page book contains cancer information with awareness symptoms listed for 21 different cancers, alongside contact details for support groups and National organisations offering help and advice.



More detailed information on support groups can be found on the website:

[www.sussexcancer.nhs.uk](http://www.sussexcancer.nhs.uk)

If you haven't yet got a copy of this booklet or would like to receive more copies for your group

**contact:**

**Mandy Lynch on 01273 574801**

## Help us to help others

If you are a patient or carer reading this newsletter for the first time and would like to help improve cancer services in Sussex, then why not join the **Partnership Group** and get involved.

We need more cancer patients and carers who wish to have a say in local cancer services.

If you feel your experience - good or bad - could benefit others, we would love to hear from you.

**Phone 01273 574801** or just come along to one of our meetings - the dates are on page 3.

[www.sussexcancer.nhs.uk](http://www.sussexcancer.nhs.uk)

