

Patient Partnership GROUP NEWS

Welcome

Welcome to our second newsletter. We hope you enjoy reading about the work and accomplishments of the group, as well as our members' individual articles.

For my part, I took over as Chair in December 2006 and it has been a challenging and very rewarding experience. I admit to being somewhat apprehensive at first, as I was stepping into the shoes of someone who had done the job very able since the group's inception in 2003.

Darshani had been the Facilitator as well as Chair and was going on maternity leave, plus the group really needed a service user to take up this role – so this is where I came in. Fortunately, only a couple of weeks before this, our group had held an away day where we devised an action plan for the next year, so this gave me a good starting point for the direction of our work.

For the large part, I am pleased to say that we have achieved most of our goals we set ourselves and those areas we have not successfully completed (i.e., establishing links; giving talks with and to other voluntary sector groups across the locality) will give us 'food for thought' for the future.

Successes over the past year have included our work and developments in areas such as end of life care; producing an information leaflet on communicating significant news; individual locality directories of local organisations for patients as well as an information leaflet for breast cancer patients. We have also been doing a lot of work on travel and hospital transport costs, but this item has yet to be resolved to our satisfaction.

Many of our members have also been active

participants on various Tumour Advisory Boards and Network Boards, attending relevant conferences, study days and national events connected to the work of the PPG. All attendees then report back to the group, thereby keeping us up to date with events, both locally and nationally.

I am extremely proud to be Chair off such a great band of people who give their time freely and openly, with commitment and enthusiasm. Each person has brought a wealth of knowledge and personal experience that enriches the group and which I value very highly. As new members continue to join us, we trust that we will grow stronger and stronger as time progresses.

My sincere thanks goes to each and every one of my fellow members for all the hard work and efforts they have individually and collectively contributed to the team's achievements over the past year.

Congratulations to you all. I hope the group will continue into 2008 and beyond, because patient partnership work has come a long way in recent times, but there is still much more work to be done, via the patient voice, before we achieve a 'smooth ride' for every patient on the cancer journey.

In ending, I would like to say a warm thank you to Paul and Caroline, who have acted as co-facilitators during Darshani's absence. They provided me with excellent guidance, support and advice; I couldn't have done it without you – thanks guys!

Now please read on and enjoy our news and articles ...

Pam Iveson
Chair, Patient Partnership Group

NASIM PANJWANI – WHY I JOINED THE PATIENT PARTNERSHIP GROUP

I was diagnosed with breast cancer in April 2001. Prior to this I lost my mother to breast cancer in 1990. At that time there was not much information or support available in different languages. I wanted to raise awareness, especially amongst Black and Minority Ethnic communities. I started by giving talks and talking about my personal experience. I was denied a mammogram at 37 years of age, even though I had a family history.

I had to fight for 5 years for a scan, after which I was told simply "It is as we thought, you have breast cancer!" I was very angry because they did not listen to me and the system let me down. I wanted to be heard, to make a difference so that other women don't have to suffer the way I did.

Hence I joined the North East London Cancer Network Patient Partnership Group when it was first started in 2004 with only a few of us. This is where I met Darshani, who was our facilitator, and got involved as a patient user on the Patient Partnership Group.

It feels good to part of the group to contribute in improving cancer services. I have enjoyed our away days and networking at conferences. I have also benefited in the training provided by the group.

I look forward to further meetings and away days. I would also like to thank the group for their continued support.



Dedications

The Patient Partnership Group and the North East London Cancer Network would like to dedicate this newsletter to Anne George and Sarah Knighton, both who passed away in December 2007. Anne and Sarah were members of the North East London Patient Partnership Group and were very energetic and passionate about using their experience to make a difference in the cancer services that are provided across North East London. We would like to thank them for their valuable contribution and strong belief in the power of patient experience and the work we are involved in.



Sarah Knighton



Anne George

Caroline Moren, Macmillan Information & Support Manager, North East London Cancer Network

I joined the Patient Partnership Group to provide support for users and healthcare professionals with regard to the provision of cancer patient information and support.

The group has gone from strength to strength and has been an effective forum for assessing and feeding back on local and national development of cancer patient information.

The group members provide a wealth of both first hand knowledge and carer information that help us to produce and provide appropriate information and support materials to improve the cancer patient journey.

It is a privilege to be involved with this group. We have members who have been involved for a number of years and new members joining all the time. This assists in keeping the group motivated and enthusiastic and I am sure the group will have continued success.

With the current national work surrounding the Cancer Reform Strategy, and in particular, the emphasis on patient experience, the importance of user involvement will increase and this group will be a valuable resource to both the network and myself personally.

CANCER REFORM STRATEGY

The Cancer Reform Strategy builds on the progress made since the publication of the NHS Cancer Plan in 2000 and sets a clear direction for cancer services for the next five years. It shows how by 2012 our cancer services can and should become among the best in the world.

There has been considerable progress made on cancer over the past decade. Cancer mortality has fallen, survival rates are improving for many cancers and patients' experience of their care has improved. We have also made progress against smoking, detected more cancers early through screening and delivered faster diagnosis and treatment. Multidisciplinary teams now provide more coordinated and higher quality care for patients and there has been considerable financial investment in cancer which has helped to deliver an expanded cancer workforce and more equipment.

The NHS has undergone significant reform since the NHS Cancer Plan was published. New systems for commissioning and financial management have been introduced and we have new ways to provide patients with choice and incentivise local improvement. The Cancer Reform Strategy sets out a programme of action across ten areas: six areas of action to improve cancer outcomes and four areas of action to ensure delivery.

Actions to improve cancer outcomes are:

- Preventing cancer - Over half of all cancers could be prevented by changes to lifestyle. Taking cross-government action to tackle the major risk factors for cancer, improving awareness and encouraging people to adopt healthy lifestyles is therefore crucial to improving cancer outcomes.
- Diagnosing cancer earlier - In general, the earlier a cancer can be diagnosed the greater the chance of a cure. Late diagnosis is the major factor contributing to poor cancer survival rates in this country.
- Ensuring better treatment - We need to build on the successes we have already achieved in cancer treatment to ensure that patients have fast access to high quality treatment for cancer, including surgery, radiotherapy and drug treatment.
- Living with and beyond cancer - Although patients' experience of their care has

improved in recent years, we can do more to support and empower patients throughout their cancer journey.

- Reducing cancer inequalities - There are major inequalities in cancer incidence, access to services and outcomes, according to deprivation, race, age, gender, disability, religion and sexual orientation. This strategy therefore places a high priority on ensuring that action is taken to reduce these inequalities.
- Delivering care in the appropriate setting - New models of care can bring considerable advantages to patients. This strategy sets out a range of ways in which service models for cancer could be improved, based on two key principles: first that care should be delivered locally wherever possible to maximise patient convenience; and second that services should be centralised where necessary to improve outcomes.

Drivers for delivery are:

- Using information to improve quality and choice - Collecting and using improved information on different aspects of cancer services and outcomes is central to delivering this strategy. Better information will enhance quality, inform commissioning and promote choice.
- Stronger commissioning - Everyone with a commitment to delivering world class cancer services should have a role to play in helping deliver this strategy. However, strong commissioning will be particularly important in driving service quality and ensuring value for money.
- Funding world class cancer care - The government is committed to funding world class cancer services but also expects the NHS to deliver value for money.
- Building for the future - New opportunities and challenges will continue to arise so we will need to continue to reassess the progress made in tackling cancer and refine our approach to reflect new developments.

Taken from the Executive Summary, Cancer Reform Strategy, 2007

Eileen Beadle, carer and widow of a mesothelioma patient

I was hurtled into the melting pot of “people affected by cancer” in the role of ‘carer’ when my husband was suddenly taken ill and subsequently diagnosed with a form of terminal cancer.

I experienced all the emotions, difficulties, achievements, highs and lows along the way. Then I was dropped into the dark abyss as ‘widow’ when my husband passed away, again experiencing all the different emotions, good and bad experiences, highs and lows.

I am now walking towards the light in a role of self-discovery, learning, advocacy and service user representative.

Having trod these boards through my journey, I can now use these experiences in a positive way. If I can help in some small way by giving my views and sharing my experiences, whilst at the same time gaining empowerment, enjoyment and a sense of achievement, then it gives my journey some meaning and I can maybe walk with more strength.

Pam Iveson – Why join a Patient Partnership Group?

Since being diagnosed with cancer myself in early 1984, six months after my others death from the disease, I have believed that patients ultimately hold the key to better treatment and cancer journey.

My experience at that point was one of the patient being told what was going to happen – ‘doctor knows best’ without any choice, involvement or input from me. So, following my first lot of treatment I joined a small group of cancer patients who were starting a support group with the idea that together, we could change things and help educate/empower patients through information and self knowledge. After 16 years working with this group (which still continues to thrive) and following my second recurrence and further treatments, I decided to move on to other things.

I had already done some work as a user representative in various situations such as on my local hospital’s Cancer Management Committee; as a reviewer in the first pilot Peer Review; as a Macmillan Ambassador in 2000 and members of the Better Deals campaign in 2002/3.

Over all this time I had seen things gradually change, from patients having no voice or involvement in their treatment/care to a situation where patients not only had a voice, but more importantly, were being heard, listened to and

valued for their input and experiences, as well as being encouraged to get involved. User representatives were becoming a force to be reckoned with, albeit we still needed to keep up the pressure to get the best we could, putting an end to inequalities; the postcode lottery and the fact that cancer was still seen in a negative light, with words such as ‘battle’ being frequently used by the media and others to reinforce this negativity, but the patient journey was improving.

Sadly, we are all too aware that some patients will die, but many more live with the disease and take an active role in their own destiny.

My belief is that user involvement, at all stages of the journey, is not only necessary but vital as we are the ones who can smooth the path for those who come after us. So having said all this, you now know why, when I say the invite for the first inaugural meeting of the Patient Partnership Group in 2004 I attended with interest and have been a member ever since I have found the collective voice of users is now louder and stronger than ever and Patient Partnership Groups have a big part to play in helping to strengthen this so that, eventually, instead of being passengers on the many different stages of our journeys, we become co-drivers along with our service providers.



WE ARE MACMILLAN. CANCER SUPPORT

Jamie Spencer has been working for Macmillan Cancer Support for 5 years, 2 of those in this region. His role is split in to two areas, working with people affected by cancer and health professionals to set up support groups and user involvement. It was his own personal experience that led him to Macmillan Cancer Support and the great work they do.

With regards to self help groups we can offer funding and training to help groups develop and establish themselves. We also offer funding to the Cancer Networks for the User Partnership Groups. We produce the Exchange newsletter that has many great articles from people who are working in cancer services, self help and user involvement. We are always looking for those inspirational stories, so let's get writing.

Are you a Cancer Voice? Macmillan Cancer Support needs more of you to help Macmillan and other organisations change the way services are run for people affected by cancer. Have a look at the great new website and sign on to be a cancer voice. This links to the opportunity exchange, which is used by Macmillan and other organisations that are running projects and work programmes and need the experience of patients and carers to make them work.

For further information contact Jamie Spencer (Development Co-ordinator for London Anglia and South East Region – North) on 01206 795 733 or on 07801 307 034.

MACMILLAN CANCER SUPPORT

There are exciting new free training opportunities. Macmillan Cancer Support is increasing the number of training opportunities both for people affected by cancer and Macmillan professionals. This includes face to face training, written materials and web based information. There are opportunities for groups and individuals affected by cancer. The sorts of things on offer include face to face workshops on:

- Healthy Eating for People Affected by Cancer
- Relaxation and Visualisation
- How Cancer Affects the Family
- Putting Life Back in your Group

There is also training on the Macmillan Cancer Support website. This is really easy to access. Just go into www.macmillan.org.uk and at the bottom left side of the web page is an area called Learn Zone, click on this and you will find loads to look at.

This website is for all including people affected by cancer and Macmillan professionals. You can browse through Learn Zone as a quest and look at the latest cancer news and access other areas from Learn Zone such as "Why Bother?" which is a great area for young people who want to find out about cancer and get information on healthy living.

"Cancer Talk" can also be assessed via Learn Zone which is a resource area for teachers who want to get information for schools.

Be.macmillan is also really worth looking at. Just click on Be.macmillan in Learn Zone, go to "order" and then materials for people affected by cancer and you can order all sorts of training booklets such as:

- Living with Cancer
- Financial Help Information
- Young People with Cancer

You can also register on Learn Zone which is really easy, full instructions are given. This is really worth doing as you can then do the Benefits Awareness and Cancer Awareness Courses. Don't worry it is all free and you can just look at it and keep going back to it at any time. You can use it to suit you so if you want to exit the course after a few minutes and go back to it another time you can do.

If you want to know more let me know my name is Julie Latimer and I am the London Learning and Development Manager. My post is new and my role is both for people affected by cancer and Macmillan professionals. I can be contacted by:

jlatimer@macmillan.org.uk / Mobile 07834192232.
Hope you enjoy the training opportunities Macmillan Cancer Support have to offer.

Julie Latimer
Learning and Development Manager, London



East London Mesothelioma Support

Confidential Advice, Care and Support

Have you or someone in your family been diagnosed with Mesothelioma or an asbestos related disease?

Do you want to talk to someone in confidence, someone who understands what you are going through?

Call (ELMS) EAST LONDON MESOTHELIOMA SUPPORT
(For victims, their carers, families & friends)

HELPLINE: 0800 8766 773

5pm-10pm Mon-Sat or 020 7476 3180 & leave your name
& number or e-mail: info@elms-group.co.uk

What we can do:

- Confidential Helpline
- Someone to talk to who understands what you are going through
- One to One meeting if Desired
- Advice/Guidance on state benefits associated with asbestos related illness
- Practical Assistance in the completion of benefit applications
- Introduction to specialist Solicitors
- Support Group – Self Help (If in Demand)

www.elms-group.co.uk

North East London Cancer Network – Cancer Services Directory

The experience of cancer touches everyone. It may be your own experience of having cancer, or you may be a family member, carer or a friend of someone living with cancer. Knowing what information, help and support are available may help you and your family to cope in a better way.

To assist with informing patients, their families, carers and healthcare professionals, the network produced a cancer services directory. This directory helps to guide you through some of the help and support available for anyone affected by cancer and living with cancer within North East London. It includes information about the services and organisations that are especially for people with cancer, as well as other local non-cancer organisations that you may find helpful.

In conjunction with the network Cancer Patient Partnership Group who kindly provided funding, we were able to produce printed copies of local borough specific directories that defined information within the directory to be more locally-specific for the public, patients and their carers. These consist of Barking & Dagenham; Redbridge, Havering, Waltham Forest, City & Hackney, Newham and Tower Hamlets.

People with cancer, their families and carers will probably need different help, support and information at different stages of the illness. There are two main types of information that can be helpful. The first of these is information on cancer itself. The second is information to help you live with cancer, as it can have an affect on many areas of day-to-day living. It may bring about changes in your family and social relationships, your work or your financial situation.

The time you spend in hospital is likely to be only a small part of your cancer experience. Knowing what local services are available to give you practical help and support at home can really make a difference.

For further information please contact Caroline Moren (Macmillan Cancer Information and Support Project Manager) on 0207 377 7241.



Local Involvement Networks (LINKS)

Over the last two years a number of changes have passed through Government, most recently culminating in the passing of two new Acts of Parliament. Both acts have at their core a requirement that local authorities and their partner agencies (Primary Care Trusts, Police, Community Organisations and the Fire Service) create better ways of involving the wider community in the improvement of public services.

The Government believes that health and social care services will improve if Local Authorities, NHS bodies (Primary care Trusts) and third sector providers listen and respond to the needs of people that they serve.

An outline of the key changes set out in the Local Government and Involvement in Health Bill are as follows:

- Section 116 requires Health and Social Care providers to create a Joint Strategic Needs Assessment that identifies short, mid and long term needs of the community.
- It places a new duty on authorities to actively involve representatives of local people in the provision of local services. This should go further than 'consultation' to involve people in the design and delivery of services.
- A Local Involvement Network (LINK) will replace Patient Forums and The Commission for Patient and Public Involvement in Health.
- Local Authorities are required to commission a host organisation to set up and support the LINK. The host organisation must be independent of the Local Authority or any NHS bodies.
- Authorised representatives of the LINK will be able to enter and view premises where care is delivered (not individual homes, employees accommodation or children's services).
- Authorised representatives must have the right skills and training, be CRB checked and demonstrate an understanding of patient confidentiality.
- LINKs are expected to conduct their own involvement activities and engage the hard to reach.
- All NHS bodies must also make arrangements to involve service users in the design and delivery of services, and produce an annual report on consultation.
- The Secretary of State has the power to impose duties on the people that commission services and some service providers to respond to reports/request from the LINK within 20 days.
- LINK can refer social care issues to the relevant Overview and Scrutiny Committee, and requires a response on how they intend to act on the referral.
- Financial support for LINKs will not be ringfenced or provided in a separate funding stream – it will form part of the Area Based Grant and be allocated with regard to demographics.
- A LINK will be expected to provide a one stop shop for the public to meet health and social care workers and discuss relevant issues.

Patient Partnership Group Away Day

The Patient Partnership Group have planned an Away Day which will take place on the 11th April 2008. The day will be an opportunity for the group to assess progress over the past year and plan for the coming year. The day will be facilitated by Derek Stewart from Macmillan and the group have decided to explore the following areas:

- Dealing with bereavement and loss within the Patient Partnership Group
- Increasing proactive membership within the Patient Partnership Group
- Survivorship for patients after treatment

Feedback from the day will be highlighted in the next newsletter.

Financial Report

	06/07	07/08
Income		
Balance brought forward	4549.59	4551.89
Funding	6000	5600
Expenditure		
Meeting costs and hospitality	1241.7	1148.95
Away Day	500	515
Patient representative expenses	225.25	89.94
Publications	3980.75	
Conferences / Courses	50.00	50.00
Balance	4551.89	8348

A Big Thank You

The Patient Partnership Group would like to say a big thank you to Macmillan Cancer Support for the funding they provide to support the groups activities as well as patient and public involvement work across the North East London Cancer Network.

The North East London Cancer Network Patient Partnership Group

Join us and have your say on local cancer services

Have you been affected by cancer – are you a cancer patient or carer who would like to give your views and suggestions for informing the future of cancer services

Your experience, whether good or bad, is unique to us and we would love to hear from you

Come and join the Patient Partnership Group

We meet every 6 weeks on a Thursday from 4.30pm - 6.30pm in Stratford

For further information on cancer patient and public involvement contact Darshani Mistry on 020 7377 7241

For further information about cancer patient and public involvement in North East London or information on any of the articles in this newsletter, please contact Darshani Mistry at the North East London Cancer Network at darshani.mistry@bartsandthelondon.nhs.uk or on 020 7377 7241.