



A Man's a Man for A' that

SUPPORTING MEN WITH PROSTATE CANCER

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Chairman's Message

Men are not renowned for their willingness to talk about themselves, particularly about their fears or anxieties, or even about certain parts of their anatomy. We are known for "bottling" our concerns, ignoring them and hoping things will pass. It is a way of adapting, a way we may have learned from watching fathers and grandfathers, other men.

Sharing your concerns with others – whether in a one-to-one chat or in a group – can really help. All of us in the Edinburgh & Lothian Group can tell you that: and it is particularly helpful to talk to someone who has gone through the same journey that you face. If you fear you have prostate cancer or you have been newly diagnosed with prostate cancer bottling your concerns is unlikely to help you, your partner or your friends.

So that's why we exist. Our open meetings exist to give you the chance:

- To listen to other peoples experiences
- Talk about your experience, and
- Hear the views and experience of those who work with men with prostate cancer

We work with Maggie's staff to provide support to men who are newly diagnosed, and those who need ongoing treatment. Individual members can sit alongside Maggie's staff, if asked, to talk about the experience of having prostate cancer.

We also work to contribute to the debate about diagnosis and treatment of prostate cancer; when we can we seek to make a vigorous and informed contribution!!!

The Edinburgh & Lothian Group is, for the time being, a part of Prostate Cancer Support Scotland (PCSS). This national body has coordinated local support groups throughout Scotland for several years. The national body has found it difficult to sustain its work as a voluntary body – the work to maintain the body has proved too much. PCSS is in talks with another prostate cancer charity, known as TPCC (The Prostate Cancer Charity) a UK body and an organisation with professional staff. The Edinburgh & Lothian group has been involved in these discussions, and is keen to see the discussions progress. We have also wanted to explore what alternatives there might be to joining in with TPCC. We expect to provide PCSS members in Edinburgh & Lothian with advice about the way in which we should be organised in 2010 onwards, in the next few weeks.

Please rest assured, however, that whatever body eventually "sponsors" the Edinburgh & Lothian support group we shall continue our work, our sharing, as we have done in 2009 and the previous 8 years!!

See you on February 4th 2010.

Best wishes
John Bishop



Chairman - John (Coltrane) Bishop playing some cool jazz (more pics on page 2) at the Christmas party

New Chairman and Committee Update

Malcolm Goldsmith resigned as Chairman in the summer partly due to some health challenges and the pressures of a very busy life. I am glad to say Malcolm is now a lot better and was seen to be in great form at the Christmas party. Malcolm is still on the committee and was certainly a tough act to follow as Chairman. A dinner was held in his honour by the committee and Malcolm in his inimitable style commented following the evening "it only underlines the fact that this is a very special and amazing group and it is a real privilege to be associated with it. Meeting up with people like those involved in our Group is living proof that a diagnosis of prostate cancer is not all bad news and unexpected riches can be discovered from what, at first, appears to be a descent into hell. In so many ways my life has

been improved - and whilst I would not wish such a diagnosis onto anyone it just shows that there is much to be thankful for and treasures to discover in this strange journey that we are all embarked upon".

Following Malcom's departure from the Chair, John Bishop and Peter Phillips agreed to co-chair the Group. Peter has recently resigned this position and that of Committee member but remains a member of the Group. We all thank him for the considerable work he has put into the Group and the Committee over the years. Mike Shaw and Peter Moles are new Committee members and in the next newsletter we will publish their profiles. Now though, we have a profile of our new Chairman, John Bishop who agreed to

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Irene (Larry's wife) in familiar surroundings..a bar..



Frances quizzing all..



Chic Murray telling stories with backing band looking on. "I met this chap at the Olympics. I said to him, "Excuse me but are you a pole vaulter?"; he replied,"No, I'm German, but how did you know my name was Walter."



Alistair and Gill receiving recognition for their work



Frances thanking everyone after the presentation to herself and Charlie

Christmas Party and Charlie and Frances

The Christmas party Dec 3rd 2009 was a great success . The music was provided very ably by Stewart Roberston and John Bishop with a musical quiz on keyboards from Stewart and John playing some cool jazz on the sax. Carols were led by Chris Garner, a fun quiz by Frances and some great comedy from Chic Murray (alias Jim Woodhead). Presentations were made to Maggie 's (Andrew Anderson) of £500, with a similar amount to the Macmillan Centre in Livingston. Recognition was given to the work of the Specialist Nurses from WGH helping the Group. After a raffle there was a presentation to Charlie and Frances as this was their last Christmas party in Edinburgh. Chris Garner led a lively sing song rendition of " Charlie is my Darling". On that note a special thanks to Charlie and Frances for all their work over the years helping establish the Edinburgh Group. We wish them well in their support work in Livingston. They both will still be very much involved and we hope to see them in Maggie 's at our meetings again in the future.



Frances having a dose of the Murray giggles..



More Murray giggles

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chair the Edinburgh & Lothian group with some reluctance!!!

Diagnosed in 2006 following a high PSA score, which the consultant suggested might result from his cycling habits, he was allocated radiotherapy and hormone treatment under the ProtecT study. Guided by friend Malcolm, who had had the same journey, he was able to approach his treatment in the light of his knowing what to expect! John found acupuncture helpful in maintaining his energy levels during the 5 weeks of daily visits to the Western General Radiotherapy Department. He has now had 2 years of a low PSA count, and enough rectal examinations for a life time! As a thanks to Malcolm he accepted an invitation to join the Committee and help with the National Conference. And then Malcolm stepped down – and stuff happens, and here he is Chair until a succession can be arranged. Retired from professional work John is both a celebrant with the Humanist Society and a student of the saxophone!!

Editor's Desk

Looking back over the year, a lot has been achieved by the Group e.g.. a National conference that grabbed media headlines and was a tremendous success; a variety of fund raising events; new support initiatives; considerable debate on the direction, constitution and governance of the Group; strategic input into the debate on screening (see PC Issues Making the News); a great programme of meetings verified by feedback from members. I quote Matthew Fry from Livingston ... "let me say that that my wife and I didn't really get the chance to say just how much we got from the support group meeting. I'd be the first to say that when Gill Davis mentioned the words Support Group some pre-conceived notions jumped into my head and I thought "it's full of old men moaning about their lot and I've enough to contend with without listening to all that". Couldn't have been more mistaken I'm glad to say.The talk by Mr Bollina was very informative and we were especially grateful for the time spent with the two chaps you sent over to speak to us. It helped enormously to straighten out some of my

thinking and also clarified a lot of questions I had without even having to ask them. Truth is though there is nothing quite like speaking to people who have already experienced and been through what you yourself are going through and in that sense just one visit to the Prostrate Support group has been an enormous lift not only for me but also for my wife." No more to be said..this feedback is valuable and fully encourages us all to continue with our work.

Great to finish the year with an excellent Christmas Social that was a special event particularly with Charlie and Frances moving on and a new Chairman. Remember we are always looking for helpers at meetings and we are very grateful for those who have come forward. New Committee members are always welcome and if you are up for a challenge please contact one of us.

2010 promises to be as challenging for our Support Group.

Happy Christmas and New Year to you all and we look forward to seeing you in the New Year.

Larry Foster

Fund Raising

Marathon Effort for Charity

Angela Constance, Livingston MSP who has been a consistent supporter of PCSS in Livingston, raised some funds for the cause in the summer and took part in three races in the month of May, a 10k and half marathon in West Lothian and the Edinburgh marathon at the end of the month!



Seriously fit Angela is pictured alongside fit looking Ashley Brown, Miss West Lothian

Big Band Dance Night

Charlie Hogg organised with assistance from Jim Woodhead and Stewart Robertson a great night at the Corn Exchange in Edinburgh in October. 250 people attended a night of big band swing, dancing and singing. £1800 was raised for the Group, and a great night was had by all. The music was provided by the the East Coast Big Band and the singers were the Rollin Hills with dancers from the Edinburgh Swing Band Society.



The Rollin Hills Choir



Evening in full swing



Some of the PS team having fun..

Musselburgh Golf Club The Club have just donated £350 to our Group, thank you MGC.

Prostate Issues Making The News

The Great PSA debate

On November 10th in Leamington Spa, the Prostate Cancer Support Federation, in collaboration with other related organisations held "The Great PSA Debate", to discuss the motion: "Every man at risk of prostate disease (i.e. all men over 50, and those 40 with other risk factors) should be encouraged to check his PSA every year."

Nearly 100 representatives of patient groups joined in the debate with a panel of 6 experts representing clinicians, charities and patients. With such an audience, it was not surprising that, at both the start and the end of the day, the votes on the actual motion were overwhelmingly passed with only those formally opposing the motion voting against it. However, the number who would call for formal screening reduced over the day from 78% to 59%. Kerry Napuk and Chris Garner from our Group travelled to Leamington Spa and put our case forward. For more information on what was said go to:

<http://www.prostatecancerfederation.org.uk/GreatPSADebatePresentations.htm>

ProtectT study

The latest newsletter(no 7) is now available with up to date information on the progress of the

study. Recruitment to the Study was completed in 2009.

For more information refer to the web site www.epi.bris.ac.uk/protect

The Big Cancer Conversation

In August, Kerry, Chris Garner and Peter Phillips went off to Stirling for the Big Cancer Conversation Event organised by the "Living with Cancer" group of Scottish Government. This group advises NHS on "Better Cancer Care". The idea was that patients would discuss nine issues to do with cancer care and return the outcomes to the Group to determine patient needs from Scottish NHS. All topics were covered for all cancer types, plus some more were added that were particularly PCa. Many issues raised by different cancer patients were familiar e.g. attitudes of clinicians towards patients, GP awareness of symptoms, availability of drugs, speedy diagnosis and treatment and continued support from NHS and Information.

Some news headlines .. the BBC reported recently..

<http://news.bbc.co.uk/1/hi/health/8110103.stm>
a surprise new experimental prostate cancer treatment..

<http://news.bbc.co.uk/1/hi/health/8055681.stm>
new PCa Test under development from the US

<http://news.bbc.co.uk/1/hi/health/8108831.stm>
green tea- new evidence..

<http://news.bbc.co.uk/1/hi/health/8273621.stm>
PCa Screening under scrutiny..

<http://news.bbc.co.uk/1/hi/health/8395865.stm>
New study shows coffee is good in PCa fight.

The Herald reported on the success in Glasgow (Beatson) of Oxygen treatment for specific cases.

New screening tests reported from Zero (the US Prostate Cancer Support web site) to help differentiate between slow growing and lethal cancers. Two test urine, another is a blood test and the fourth is to be used during biopsy to assess potential spread risk of cancer.

Ipilimumab - new experimental antibody drug for men with advanced PCa at the MAYO Clinic, USA.

Daytime Meetings – Maggie's

Early in the new year we will be launching a process to enable patients to see a fellow member of the Group if they wish during the daytime at Maggie's. This was brought about as a result of a perceived need that although the evening meetings are successful, they are infrequent, and therefore it is important that we can offer a rapid response to new patients wanting to talk to a member face to face rather than just a telephone call or email. A sub group of members who have volunteered have been selected to help run this. Initially, we have focussed on Edinburgh based members who are also on email to assist with coordination but this could change. For more information talk to Larry Foster or Andrew at Maggie's.



Group Meetings

Recent meetings in Edinburgh at Maggie's Centre

June 4

The meeting was very well attended considering it was holiday time. The first part of the evening Members were split into Treatment groups after which Barbara Mayne, a Research Nurse, shared her work at WGH. Conclusions and priorities from the Conference were discussed. This resulted in a show of hands to press GP's to respond to PSA requests, to support research into an improved PSA test, and to seek improvements to local services. The meeting finished with a general discussion on future topics.

September 3

A very full Maggie's. The meeting started with 45 minute sessions split into different groups. New members (newly diagnosed or newly treated), surgery, radiotherapy, hormone treatment and watchful waiting. After these groups Larry Foster facilitated a rehabilitation session running simultaneously with an End of Life talk/discussion run by John Bishop and Peter Phillips. The final 30 minutes were devoted to Suzy Mercer from The Prostate Cancer Charity who gave an interesting talk with slides about the Charity, its initiatives and donations for research etc across Scotland and the UK.

November 5

Dr John Steyn (GP from Edinburgh) kindly came to talk to the group about PCa from a GP's perspective. Excellent talk and presentation clearly showing how low down PCa is in the day to day life of a GP. Dr Steyn showed statistics illustrating the reality of this and gave a very frank and

comprehensive account of his experiences resulting in excellent questions from the audience.



Dr John Steyn at Maggie's

Recent meetings in Livingston at the Macmillan Centre

August 5

A full meeting with Members split into Treatment Groups and followed by Members talking about their own experiences. Specialist Nurses were in attendance to assist.

October 14

Livingston Group was delighted to have the eminent surgeon Prasad Bollina attend to talk to the Group about PCa from screening through to treatment and the outcomes. A very interesting evening that was well received by all.



Mr Prasad Bollina at the Macmillan Centre

Group Notices

Sad News

Sadly we have to report that two of our members have died since the last newsletter.

John Howard and Robert Craig. Our thoughts are with their families and friends.

Group Meetings 2010

Edinburgh Support Meetings

All on Thursday at 7 pm at the Maggie's Centre, Feb 4, April 1, June 3, Sept 2, Nov 4, Dec 2.

Livingston Support Meetings

All on Wednesday at 7 pm at the Macmillan Centre, Livingston, Jan 20, March 17, May 19, Aug 4, Oct 27.

Web Links

SOME USEFUL WEB LINKS..

- www.prostatescot.co.uk
- www.prostatescotland.org
- www.cancernet.co.uk
- www.prostate-cancer.co.uk
- www.prostate-cancer.org.uk
- www.cancerhelp.org.uk
- www.epi.bris.ac.uk/protect
- www.prostate-link.org.uk
- www.hibernationdiet.com
- www.maggiescentre.org
- www.scan.scot.nhs.uk
- www.ustoo.com
- www.after-cancer.com
- www.scotlandagainstcancer.org.uk
- www.prostatebrachytherapyinfo.net
- www.zerocancer.org
- www.prostatecancerfederation.org.uk

Bits and Pieces

New coffee machine at the HEBA Centre - WGH

Peter Phillips initiated the supply and donation by the Group of a very welcome coffee machine for the HEBA Centre at the WGH. Gratefully received!



Rita O'Dea enjoying a caffeine injection from the new machine

Karen Campbell- Physio for post intervention recovery

We are pleased to report that Karen Campbell our urological physio had a baby in May and hopefully will be back amongst us soon. Congratulations Karen.

Email

Remember that we have an email service that allows members to receive Notices via email and also interesting information about Prostate Cancer Treatments etc. This is obviously less expensive for the Group so if you are on email and have not given us your address please email pccseandl@gmail.com.

Useful Contacts

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