



Did you miss the Opportunity?

Understanding Yourself—a real guide to Supported Self Management

Did you see an advertisement for the 'Understanding Yourself' event at the Holiday Inn, Impington on 18th May? Did you think – "It's not for me?" - I was there and can only say that if you have been treated (or are being treated) for cancer, or are a partner or close relative of such a person – IT WAS FOR YOU!

If you thought you had something better to do I can only say it must have been exceptionally IMPORTANT for you to miss out on this event because it had the ability to change your life for the better. I am certain that IF all the people who could have learned from or benefited from the sessions had accepted the invitation, they would have needed a bigger venue (or more events!).

It started with some light refreshments whilst I strolled around the 'marketplace' of organisations that may be able to provide help or assistance. During this time, I (very wisely) sneaked into the hall and booked myself a seat that suited me.

Then (after a **Welcome**) the sessions

Keynote session: Supported Self-Management: *there was quite an emphasis on 'supported' – we can't do it all ourselves without some support even if it is only to understand our health behaviour changes, then*

Diet & Nutrition: *how to keep yourself healthy during and after treatment,*

Living with Fatigue: *this seems to come with all types of treatment!*

Exercise and Cancer: *keeping active during and after cancer treatment.*

And finally (in the most relaxing voice you can imagine), Relaxation techniques: reducing stress with Aneesh Shrivat (Clinical Psychologist Cambridge Maggie's Centre). You can get a full session on a Tuesday at 11:30 at Maggie's in Puddicombe way – you don't have to wait for another 'event'.

I don't know whether these sessions will be different at future events but I am sure they will be relevant and helpful talks about how to cope with changes in food tastes and dietary needs, emotional issues and problems, and of course provide the physical/physiotherapy help and guidance that is available. I am sure that you (as I did) will leave saying "I didn't know that before" (although we might have different reasons!).

If you did see an advertisement and did not come, you should look out for another session and COME! As I don't know how to use a crystal ball (maybe I would have tried to learn if I had one!), I don't know what the next 'health and wellbeing event' will be called, when it will be held, or how it will be publicised. I am sure it will be widely publicised and I will include a reminder in a future bulletin if I know of it well enough in advance! It could even become a regular 'appointment' at some point in future treatment plans.

Whether it is compulsory or voluntary I can only say come and, like me, learn how to live with and beyond cancer and the side effects of treatment.

Tony Mitchell



The CPPG Bulletin is now available Online!!

We realise that you may not be a regular attender in Oncology/Haematology Outpatients –so you may not be aware when the next edition is available. Of course, if you are reading this in a paper copy we hope you will take it home with you to read and enjoy. We hope that you do enjoy this publication and so may like to know that you can read this and future editions at your leisure at home – they will be available online. You can find a link to the latest edition (and any earlier editions that are available) on the CPPG page of the Addenbrookes website.

The CPPG page can be found at:- <https://tinyurl.com/cppgpage>



A Well-Deserved Award



Recently Lead Cancer Nurse Elaine Chapman (centre) was awarded the prestigious NHS England Chief Nurse's Silver Award badge.

This Silver Award recognises individuals who have excelled in their performance, going above and beyond to deliver nursing excellence in either clinical practice, education, research, engagement, leadership or the diversity agenda. CUH is among a small number of organisations to have individuals who have been awarded this prestigious Silver Award so far.

Elaine was given the award due to the work she has led in cancer care to ensure that service users are always meaningfully involved in the evaluation, design and delivery of cancer services, under the title of co-production. Special emphasis was placed on her ability to raise the profile of working in true and equal partnership with people living with cancer.

Elaine is one of the two co-chairs of the CPPG and her work has certainly been an important factor in making the CPPG known within CUH and promoting what we can offer in the way of patient/carer involvement and co-production.

Pictured Lenja Bell (Co-production Lead / CPPG coordinator), Dr Eileen Rubery (CPPG Patient Co-chair) with Elaine and other CPPG members at a recent committee meeting.



Please write to ME

Please write to me – seems a most reasonable request. Why should letters from hospital clinicians be SENT to 'my GP' with a copy (possibly) sent to ME (the patient)? As I write this it is almost a year since the Academy of Medical Royal College's issued guidance that MOST outpatient letters should be written directly to patients.

The CPPG has organised a co-production initiative aimed at encouraging all clinicians who write outpatient clinic letters to write all possible letters directly to patients. The GP still needs to know everything that has previously been included in GP letters such as details of treatment given and medication details. The letters must include everything that the patient needs to know AND everything the GP needs to know!

We entered into discussions with hospital consultants, GP's (who were concerned about the possible loss of information) – and of course – patients! The result of our work is a package which we will present to the Addenbrooke's Cancer Board for approval. This comprises a covering letter, detailed guidance and rewritten example letters to aid clinicians when making the change. We hope that the result of this initiative will be a sustained move towards having letters about OUR health written to US.

What is the CPPG and what does it do?

The CPPG (Cancer Patient Partnership Group) is based at Cambridge University Hospitals (CUH) and is comprised of people affected by cancer: either by receiving treatment, carers and hospital staff involved in the delivery of cancer services. In partnership, the group works hard to improve the experience of cancer services for all. The CPPG is a major part of the CUH implementation of the NHS Co-Production Policy, representing patients in many committees and steering groups including the CUH Cancer Board, which looks after all cancer care and suggests ways to make it better.

How to join ? -

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This bulletin is produced by members of the Cancer Patient Partnership Group with the articles written by members of the group. We hope that you will find it interesting and informative as they share their experiences and details of their work with Cambridge University Hospitals (CUH). **Any views expressed** are those of the individual authors and are not necessarily those of all members of CPPG nor of CUH.



The Choice The Story of a Prostate Cancer Survivor

Editor's note Although this article is about prostate cancer, many of the points could be relevant to other types of cancer and other treatments. Where a choice of treatment is offered to a patient, they and their families could be faced with making similar decisions guided by their own priorities. I hope you will read it and that you will find it useful.

In 2014 I was told that I had prostate cancer and that either a robotic assisted operation or radiotherapy would be equally effective treatments. As I had no symptoms, I had approached this appointment in an optimistic mood thinking that the test results wouldn't be serious. However, I've learnt to expect bad news in appointments where you're seen by two members of staff and are offered free tea and biscuits on the NHS!

The package supplied to me provided a lot of information on the risks and potential side effects of robotic assisted radical prostatectomy operations and radiotherapy treatments. It was my choice. I spent two weeks devouring information on the internet, contacting Prostate Cancer UK and other organisations able to provide useful information. The fact that my brother had spent two years fighting a losing battle with colon cancer helped me to focus on what really matters and what doesn't so much. I decided that MY personal priorities were:-

- 1) Above all else I wanted the treatment that would be most likely to provide a cure;
- 2) I'd rather not be incontinent on a long-term basis;
- 3) I'd rather risk erectile dysfunction if it increased my chances of survival.

As always, the internet was awash with stories about "wonder" treatments that claimed to provide a cure without side effects. I choose to ignore all these and concentrated on the treatments that had a proven track record with the NHS (an organisation I trust more than the profit motivated health systems in the USA and elsewhere).

I watched video footage on the internet of robotic assisted radical prostatectomy operations and, being an engineer and computer programmer, I was attracted by the benefits of the technology. Also, my understanding (warning – I have no medical qualifications) is that PSA blood tests after a prostatectomy are likely to be more consistent and reliable than after radiotherapy. Finally, I read that there was the small risk that radiotherapy treatment for prostate cancer could trigger colon cancer which, given my brother's situation, was a risk I was keen to avoid.

Five years later I've no reason to regret my choice to have a robotic assisted operation. Although the operation wasn't like "a walk in the park" and there were a couple of relatively minor problems, the treatment I received from the NHS was wonderful and I consider myself to be really, very lucky. Especially being an old codger in my 60s, erectile dysfunction is a minor problem relative to the fact that I'm alive and well. After all I still have my memories.

Join the CPPG: We need your help to make a difference

Patients and carers are warmly invited to join the CPPG. To find out more, please email Lenja Bell (cppg@addenbrookes.nhs.uk) or telephone on 01223 216842.

Please leave a message if no one is there to answer, and we will get back to you as soon as possible.



A New Look And Feel For Oncology/Haematology Outpatients

The CPPG has had the wonderful opportunity to participate in the refurbishment of Oncology/Haematology Outpatients. The chance to be involved was so exciting as I, having spent so much time there, know that it is soulless, badly lit and crowded.

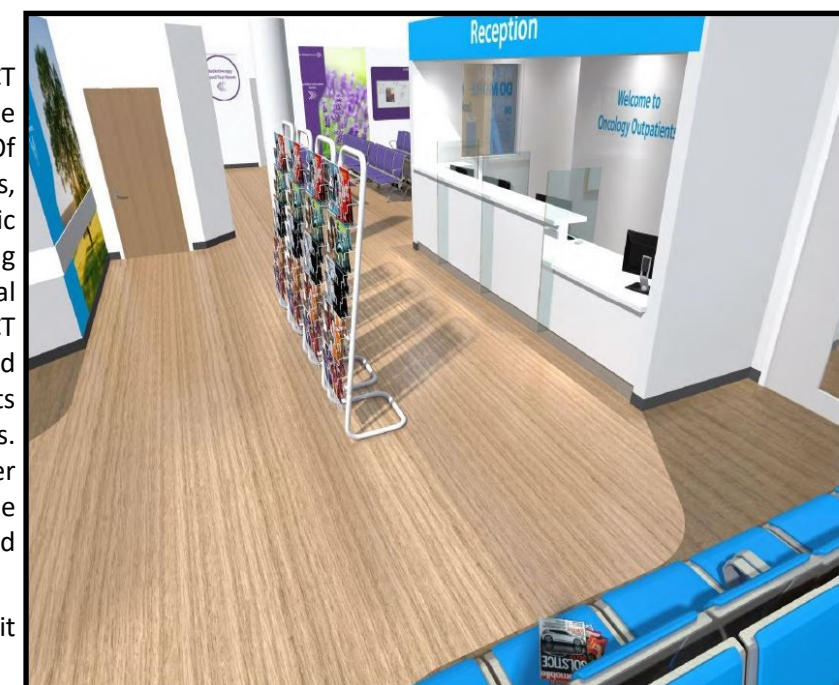
Seven CPPG members had a workshop with a similar number of staff. Almost nothing was excluded from discussion! We started by listing the many issues we could think of - from the queuing and waiting issues to the lack of unisex toilets.

A particular issue identified was the problem of patients facing a long wait having to stay in the waiting area. This not only increased congestion in that area but limited their choice of refreshment, etc. As a result of this feedback, patients are now able to ask for 'buzzers' (from reception) so that they can leave the waiting area to go elsewhere (e.g. the shops at the main concourse). The buzzers are used to tell them to return ready for their appointment with the clinician.

There were so many positive suggestions to improve not just the decor, but the atmosphere. A second workshop looked at possible layout changes and passed these suggestions to the professional interior consultants whose job it is to incorporate these changes into the new design. I hope we can achieve most of these and am eagerly looking forward to a better use of space, a more informal layout and cutting down the queues of people waiting to sign in or make their next appointment.

A vital partner in this project is ACT (Addenbrookes Charitable Trust) whose fundraising has made it possible. Of course, this really means patients, carers, staff and members of the public contributing by simply giving, giving through 'gift aid' (where the actual amount of the gift is augmented by ACT reclaiming the basic rate income tax paid by the donor on the gift) and by bequests in the wills of other generous donors. Please consider joining these other generous people by 'tapping' on the collection points or by making a gift aid gift or a will bequest.

To donate to ACT's Cancer Appeal, visit www.abigc.org or call 01223 217757.



If an article has helped you in any way, we would love to hear from you.

Send a note to Editor, CPPG Bulletin, Box 193, Division B, Cancer Services, Addenbrooke's Hospital, Cambridge, CB2 0QQ or email cppg@addenbrookes.nhs.uk