

Moving Forward & Living Well.

Summer 2014

Issue 3

Hello... we have been very busy since the Spring Newsletter and so would like to briefly update you on how the Transforming Cancer Care in the Community project has moved forward and tell you about our new plans.

So, our 2nd Patient Conference went very well. The same key important subjects were covered but with some subtle variation, particularly The Laughter Therapist. Truthfully, attendees could neither have been surprised nor disappointed it was just weird, but funny, indescribable, quirky and people did find themselves laughing!

Once again friendships were formed and details swapped between people who unexpectedly found a connection and a common bond with someone they met.

This for us is the most satisfying outcome. From experience we know how beneficial it is for people to get together and share experiences. Sometimes we try to facilitate this but you can't beat it if it just happens naturally.

We organize different activities to bring people together for just this purpose but it can be a struggle. We always encourage people to come to our groups or activities but 'patients' tell us 'it's not for them, that they're coping, that they don't need to talk'. If we can persuade them to come along, they soon find that they do enjoy meeting other people who understand how confusing it can be to live with the complex emotions cancer brings with it. Our Friday yoga and Coffee sessions really are proving to be a popular meeting spot for patients who have recently been diagnosed with cancer, going through or just finished treatment and for those who are 'living' with cancer and trying to hold together work and or family. This is a positive group of people who are active and looking to move on with their 'new lives'. They have found it beneficial to spend some

Every Friday
Holiday Inn, Brampton
Race Course.

In the Coffee Lounge

10am-12md

Come along & meet us.
Relaxing atmosphere, free
yoga session,
Confidential &
professional advice.



Patient Conference

Living with Cancer

November 6th 2014

Free to patients & carers

Lunch & refreshments
included.

More information
coming soon!

time with like -minded people. Even the men! The yoga is optional but please give it a try, enjoy an amazing hour of relaxation with Cherie doing some chair based yoga. Its free, you can buy refreshments from the bar and we often leave at midday and the chatting is still going on. This is a great place to find a little support during an unsettling time.

Hunts Community Cancer Network. The bonding for patients benefiting from the Transforming care project has been so successful that they have formed a cohesive group. The purpose of this group is to grow a network of patients, families and businesses to support the continuation of the community cancer project. At present we have some funding towards training, speakers for the conferences and equipment. We want to sustain this once the pilot ends. Patients and local businesses can help us do this. We shall talk more about this developing network in the next newsletter, also how we and the patients have linked with GSCE students at Longsands Academy to design a web site for the network.

If you come along for a coffee on Friday you can find out about other groups that you can access such as Meditation, Pilates and French lessons. All these activities are there to support those of you with a newly diagnosed cancer, finding it difficult to move on after cancer treatment or those living with their cancer and trying to cope with work or families. Please give me a ring or Email me if you are interested.

Late consequences of treatment Last issue we asked for your help. We would very much like you to contact us if you are 6 months post Cancer treatment having had any of the following

- * Chemotherapy (particularly 5FU)
- * Radiotherapy to your pelvic area (Prostate, Ovarian, cervical or Bowel cancer)
- * Bone Marrow Transplant

And if you answer yes to any of the following questions.

Are you woken in the night to open your bowels?

Do you have troublesome urgency to open your

bowels and/or faecal leakage/soiling?

Do you have any abdominal symptoms that prevent you from living a full life?

In the past it has been thought that these late effects of treatment were something that you had to put up with. They were thought to be an irreversible result of treatment. That might be true in some cases but we now understand more about why they happen and in some instances can improve or eradicate these distressing symptoms. Thanks to the enormous generosity of one of our patients, we have been donated a new piece of equipment that can enable us to diagnose certain causes for these symptoms.

What else is new? Very shortly ladies with Breast cancer who are within our pilot catchment area and have a low risk of recurrence will be able to benefit from our new follow up service.

At present after treatment, patients are expected to come back to the hospital for regular follow ups. This is a very out dated process.

In spite of these follow-ups, many patients say they feel abandoned after the end of their course of active treatment and that they have little support in trying to rebuild their lives, work, education, self-employment, relationships, fitness and priorities.

It is now known that follow up can be better managed with a process known as Self-managed aftercare.

Re-designing this service involves community support right from diagnosis and an extensive interview at the completion of treatment. Patients are then followed up with a community cancer key worker. At any point that concerns are raised by either the patient or cancer nurse specialist the patient will be fast tracked back to the consultant.

Mammograms and all other planned interventions continue. The great advantages of this improved system are;

Patients feel that because they have a follow-up appointment in the next few weeks they can wait until their next appointment if they have a problem
OR

They can ignore suspicious symptoms as they have just had a follow-up

appointment and thus it cannot be serious.

This system gives patients better psychological support, enabling them to come to terms with the diagnosis and treatment and resume as normal a life as possible as quickly as possible. It provides more opportunities to give advice on nutrition, exercise and healthy lifestyle, improving the reducing the risk of recurrence. Recurrences are diagnosed earlier with this improved rapid and timely access for patients with suspicious symptoms. We hope that once we have this system up and running for breast cancer we will roll out the same benefits for colorectal and prostate cancer patients with a good prognosis.

Red Flag Symptoms. We are underway with a campaign to raise awareness about Spinal Cord Compression. This is often diagnosed late and patients fail to report symptoms. Most common with Breast, Prostate and Lung cancers and also Multiple Myeloma.

If you experience any of the following please talk to your health professional

Pain or tenderness in the middle or top of your back or neck

Severe pain in your lower back that gets worse or doesn't go away

Pain in your back that is worse when you cough, sneeze or go to the toilet

Back pain that stops you from sleeping

Numbness, weakness or difficulty using your arms or legs

A band of pain down your arm or leg or around your body

Changes in sensation in a part of your body, for example pins and needles or electric shock sensations

Not being able to empty

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