

CENTRE STRATEGY

April 2011 – March 2014

Executive Summary

Over the next three years we plan to continue with our focus as a community-based cancer support and information service for Wandsworth and nearby areas. At the same time, we are making available innovative approaches piloted at the Centre to people throughout the UK who aren't otherwise able to access them.

The most striking example is the Healing Journey developmental groupwork programme, which helps people to deal with stress and develop resilience. The programme, which was developed and researched at the Ontario Cancer Institute in Canada, was introduced into the UK by the Centre.

We have adapted the programme for UK use, and piloted and evaluated the programme courses.

The need for our services

The need for therapies, groupwork, information and

home visits for housebound is as great as ever, so we plan to continue to provide and develop those approaches. In order to respond to the needs of increasing numbers of people living long term with the after-effects of cancer.

We also plan to:

- develop more outreach activities in the local community
- hold more social events to reduce people's isolation,
- develop services aimed at helping people with the difficulties they have about returning to work.

Premises

Ensuring a permanent premises solution will also be a priority over the next three years and we will focus much effort on developments that are likely to bring about permanent premises close to Clapham Junction within 3- 5 years.

Centre Mission

The Centre's mission is to:

- provide information, support, education and complementary therapies to people whose lives have been touched by cancer, recognising and respecting their individual needs
- reach all sections of the community
- encourage the users of our services to give feedback on our services and to be actively involved in the Centre's work
- advance health through health promotion work.

The importance of continuity of care

One of the foundations of our work is the way in which we are able to provide support to some of our members over a very long period, as they live with the long-term impact of cancer and its treatments, have recurrences or deal with the development of further cancers.

This kind of long-term help is unusual and greatly appreciated by those who take it up.

In the Appendix, you will find client stories that illustrate this theme.



Two Centre members at our 25th Anniversary lunch

Our relationship to government policy on cancer services

The Government's cancer strategy was updated in January 2011 in *Improving Outcomes. A Strategy for Cancer*.

Beginning with the recognition of the growing number of people who will be affected by cancer in the future, the document underlines the importance of providing supportive care and help with developing self management skills:

“There are now about 1.8 million people living in England who have had a cancer diagnosis. By 2030 it is anticipated that there will be 3 million people in England living with and beyond cancer....People living with and beyond cancer often have specific support needs which, if left unmet, can damage their long-term prognosis and

ability to lead an active and healthy life.

Among the changes needed to respond effectively to these additional needs are:

- a greater focus on recovery, health and well-being after cancer treatment
- a shift towards support for self-management, based on individual needs
- access to appropriate information and support including access to lifestyle advice and interventions such as physical activity programmes and vocational rehabilitation support.

More needs to be done so that cancer survivors have

the care and support they need to live as healthy a life as possible, for as long as possible. We want to see improvements in the outcomes which are particularly relevant for people living with and beyond cancer, such as reducing the proportion of people who report unmet physical or psychological support needs following cancer treatment.”

We see the work of the Centre, alongside the network of other cancer information and support centres and groups throughout the UK, as making a significant contribution to meeting the psycho-social needs outlined in the document.

See section 2 on our Services below.

Key elements of the Centre's strategy

1. Positioning

a) The Centre will provide a welcoming place offering emotional and practical support, & information in diverse forms for those affected by cancer in the local community in Wandsworth and nearby boroughs.

b) We aim to continue to develop innovative & transformational work through educational programmes that develop self-care skills and enhance wellbeing and resilience, in particular the Healing Journey Programme,

and meditation and mindfulness courses. We will evaluate these approaches consistently, and will make available the findings from this development work as widely as possible in the UK.
Timing: see 2 c).

“ I attended the Centre when I was unwell and at a particularly low point in my life.

I would not have coped with the illness without the counselling and support I received. The professional, caring support I was given is something that friends and family, however sympathetic they may be, cannot provide and I found it vital to my recovery.

CENTRE USER

2. Services

We aim to continue to provide very high quality therapies, specialist information and advice, developmental groupwork (see 1b), and support groups for disadvantaged groups.

We will extend our wellbeing services in order to support those now living for many years following their initial cancer treatment.

We aim to add to our core support, information, therapeutic and groupwork services by:

a) running a series of well-resourced themed events that are lively and varied, and aimed at meeting the needs of carers as well as people who have/have had cancer.

Timing: twice a year starting in May 2011.

b) recruiting an expanded pool of highly trained volunteer therapists in order to extend the range of therapies we offer (for example increasing the different types of massage).

We also want to extend the groupwork and courses offered by piloting and evaluating new approaches such as

rehabilitation through exercise programmes.

Timing: this work is continuous.

c) seeking the most effective ways of disseminating the Healing Journey Programme in the UK and of developing approaches to mindfulness that are adapted to the needs of people with cancer.

In particular, during 2011, we aim to pilot and evaluate an on-line version of the Healing Journey Programme for use by people unable to access the on-site courses owing to health and disability or location.

d) developing our re-launched Home Visiting Service and seeking individual supporters to help ensure the future of this service.

Timing: to recruit and train new volunteers by July 2011 and to arrange events to inspire new supporters, starting in summer 2011.

e) seeking to re-launch outreach work with minority ethnic populations in our local communities in order to contribute to the national goal of reducing inequalities in cancer

services, by focusing on cancer awareness and on activities aimed at increasing wellbeing and developing skills needed to lead as constructive a life as possible.

Timing: by the first part of 2012.

f) developing programmes of physical exercise to complement our psycho-educational programmes.

Timing: to begin offering a Healthy Steps Programme by the autumn of 2011.

g) piloting and evaluating a series of workshops on managing change workshops as a way of offering help with the difficult transition back to work for those who have completed their cancer treatment.

Timing: from first quarter 2012.

Outcome measurement

We also plan to introduce a systematic method for measuring the impact on people's quality of life of the different therapies that are at the core of our work.

Timing: from June 2011.

“ **It's difficult to describe the grief and fear, and sense of bewilderment and helplessness, that I experienced at the time of my diagnosis of breast cancer.** At the end of my treatment, I went to the Centre and will not readily forget walking into that extraordinary combination of calmness and vitality.

I was met with great warmth and sensitivity and was given time, space and choice. I was also, very importantly I think, helped to find ways of helping myself and getting in control of things again. **It was a completely transformative experience.**

CENTRE USER

3. Premises

a) We aim to **move to premises that will give the Centre a satisfactory home** for the next 3-5 years by April 2011.

We aim to maximise the opportunities provided by the new premises to work with the local community, and to build partnerships with other health & social care organisations on the site.

b) We aim to **build on the embryonic partnership we have established** that will enable us to provide permanent premises for the Centre by 2014 – 2016 in the location that works best for our service users, which is close to Clapham Junction station.



Yoga class at the Centre

4. Fundraising

a) We aim to **increase our focus on raising unrestricted income** through donors, events (especially locally-based ones) and a legacy campaign, in order to reduce our dependency on specific grants.

b) We aim to **increase the links we have in our local**

communities, through profile raising and a programme of activities and events
Timing: from summer 2011.

c) We will **work with the new health and local authority personnel and structures** responsible for commissioning

health and social care services in the future.

Timing: from April 2011.

d) We will continue to **maintain and build excellent relationships with the grant-making trusts and companies** which support our work.

5. Partnerships

a) We will further **develop our long-term partnership with cancer services at St George's NHS Healthcare Trust** through collaborating with the new Cancer Information Service on the hospital site.

Timing: from summer 2011.

b) We will **contribute to the local Health and Wellbeing Partnership** being set up to advance the implementation of the new commissioning arrangements for health and social care.

Timing: from summer 2011.

c) We will **invite London-based cancer support services to attend networking meetings several times a year** under the auspices of the National Conference of Cancer Self Help Groups; to collaborate in practical ways such as seeking cost-sharing schemes, exchanging ideas that work; and to form alliances to develop services where appropriate.
Timing: twice a year from June 2011.

d) We will **initiate discussions with the other health & social care organisations based in the Centre's premises**, in order to seek cost-sharing solutions or other practical ways of working together.

Timing: begin by September 2011.

“The Information Service partnership between the community-based Paul's Centre and St. George's Hospital is unique.”

Macmillan Service Development Manager

6. Marketing and Communications

We aim to increase the Centre's local profile by:

a) **developing PR and communications workstreams** including:

- i) Centre literature and website
- ii) ICT and social media

- iii) local radio and papers
- iv) links with health professionals
- v) advocacy with individuals and organisations.

Timing: all workstreams to be in action by October 2011.

b) **seeking a partnership with high-level business consultants** to develop our promotional materials, our website, and the ways in which we communicate with the public.

Timing: from autumn 2011.



It's so important that this kind of place exists. It was a terrible shock when I was diagnosed with breast cancer, especially telling my daughter who was 17 at the time. I had a horrible time following surgery – I was sick and in pain and then when I started chemotherapy, I was very poorly and spent five days in hospital with a bad infection. In the middle of it all, my ex-husband who had been very supportive, died suddenly from a heart attack. Life was like a roller-coaster every day and my emotions were all over the place.

When I found the Centre, I felt so welcomed, so at home. It was very calming, as before I came, I couldn't relax and I was stiff and anxious all the time. I had a course of massage and reflexology and I had counselling which I felt helped to release something in me. I have also met some lovely people who are in the same situation as me and it has been helpful to see how they are coping and to share information and ideas. When I found the cancer had come back in the other breast three years on, **it was such a relief to come into the Centre and to feel so supported and so cared for.**

It's great knowing that the Centre is still there for me as I try to get my life back together."

CENTRE USER



A reflexology session at the Centre

PAUL'S CANCER SUPPORT CENTRE

Tel: 020 7924 3924 www.paulscancersupportcentre.org.uk
Reg charity no: 1128295. Company registration no: 06802920.

STORIES of SOME LONG-TERM CENTRE MEMBERS

Paul D'Auria

Paul was in his early 30's when he was diagnosed with thymoma, cancer of the thymus gland, and told that although there were treatments that could be offered, the cancer was incurable. He was told he had six months to live.

As ever, Paul took a proactive approach and sought other opinions. As a result Professor Sikora referred him to Mr Kaplan a very skilled surgeon at the Royal Brompton, who removed 77 tumours from Paul's chest including one orange sized one, took out a lung and part of the diaphragm.

This was obviously traumatic surgery, but it enabled Paul to start on the long journey he took, involving many bouts of treatment, many times when he decided to defer treatment until his own time, and adventures into many of the complementary and unorthodox methods on offer for prolonging life and increasing wellbeing.

That he lived for 15 years rather than 6 months is both a result of his determination and a sign of hope for us all today.

An inspiration

It wasn't just the length of Paul's life that is an inspiration, it was the way he lived life to its fullest at all times.

I would always know when Paul was in the Centre because of the delightful way in which he made his presence felt. Although

he was quietly spoken, we were always aware of the specialness of the present moment when with Paul.

It was the same at the Royal Marsden where he received many rounds of treatment. Professor Ian Smith spoke at the memorial event celebrating Paul's life about his visits to the hospital, where medical staff were always captivated by Paul's story and how he was, rather than preoccupied with what his results showed.

Professor Smith acknowledged that Paul had taught generations of young medical staff how to listen to the patient.

Using the Centre

Paul accessed the Centre's services, not all the time but in 4 or 5 episodes over the years of his illness, during which he had some periods of wellness where he was able to get on and enjoy life.

Paul also had many reprieves, where the medics thought he was lost, but he returned. Caroline, his wife, has emphasised the importance of people with cancer having available a service that provides support in an ongoing way, not just once after diagnosis, since having cancer doesn't get any easier when more treatment is needed, and Paul and Caroline always felt the need for support in the challenging life they led.



Paul D'Auria

Paul kept working and was a very creative maker of advertising films. A couple of weeks before he died he was in Prague making a film advertising Which magazine. That film won an award and is still being shown today.

His legacy

Paul motivated and inspired so many people in his lifetime with his creativity, fun and courage. As one person said at his memorial, "he was a good example to us all. When up against overwhelming odds, you can take your life in your hands and do something about it."

This "quiet, gentle, dignified, witty and warm man", as he was described at the celebration held in his honour, is a wellspring of hope now and in the future.

Written by Petra Griffiths, the Centre Director.

Doris Campbell

Doris had very courageously come to London from the Caribbean as a young woman, had trained as a social worker and had become greatly respected in her profession.

She first came to our Centre in July 1997, having previously had breast cancer surgery and facing further surgery (mastectomy).

We immediately put her in touch with another client who had had an aggressive form of breast cancer but was then well. Doris found the support of another woman who had been in a similar situation very helpful.

As well as her anxieties about her future as a cancer patient, another serious worry at first was that she felt unable to ask for help as she had always been proud of being the helper. She worked on this with our counsellor and also attended our Support Group and later had healing sessions.

Improving health

As her health improved, Doris became proactive in encouraging other Centre clients to make the most of our services, becoming both a client trustee of our Management Committee and taking part in what was then a newly formed African Caribbean Support Group.

She continued to have long-term low-cost counselling provided by our senior counsellor and was able to return to full-time work as a senior social worker with an adoption agency.

We know she was greatly admired by her colleagues and we are proud to know we were able to support her so that she could continue her work. She also had regular talks about her treatment with our Macmillan Information Officer.

Dealing with cancer issues

Doris was troubled by the issues that black women face with the provision of wigs and prostheses, and we were able to put her in touch with the South West London Cancer Partnership Group which promotes user involvement in the local NHS, where she could channel her concerns and make things better in the future for other black women with breast cancer.

She also found that in her own community, cancer was still considered a source of shame.

In her own words

In 2007 Doris said of her involvement with the Centre:

“When I first came to the Centre, about 10 years ago, I was feeling frightened. The Centre was very welcoming and felt very safe at a critical time in my life. Whenever I’ve dropped in, the staff have always made time for me. That is what the Centre does best – provide the space and time to listen to people, so that they can explore their own experiences. **When you walk in, you feel the place belongs to you.**”



Doris Campbell with Honor Brogan, a Centre Support Officer

My sense of self was shattered following a diagnosis of cancer and 18 months of treatment. In counselling Heather encouraged me to explore my own needs rather than always looking after others. She encouraged me to recognise my own value, to explore my beliefs and how the cancer has affected me.

She helped me to develop confidence in myself again, to explore my creativity, which I hadn’t even thought about before. I still have items I made in the creative arts sessions, especially a pot I made and planted a tangerine seed which grew into a tree.

With the expansion of services at the Centre, this core part to do with valuing people has been kept at the heart of things – long may it continue.”

Illness progression

In 2007 Doris developed both liver and lung secondary tumours. She had further chemotherapy and radiotherapy treatment.

At that point she was unable to come into the Centre and received massage with a volunteer from our Home Visiting Service. She lived on her own in a housing association block up several flights of stairs

in Pimlico, with no lift, so the volunteer's visits to give her massage at home when her health deteriorated were really important. Later that year, as her health improved, she was again able to come to the Centre, receiving hypnotherapy to help with insomnia, counselling and reflexology to aid relaxation. Doris was given a very poor prognosis in 2007 and was expected to live less than a year.

She actually lived three more years and sadly died in November 2010.

Ongoing support

The range of therapies and ongoing support we had been able to offer Doris over a period of thirteen years is a distinctive characteristic of the Centre and demonstrates our commitment to help people to deal with the long-term issues arising from cancer.

Claire Morgan

I was diagnosed with breast cancer in Feb 2001 at the age of 34. At the time of diagnosis my Mum had just completed a course of chemotherapy for advanced bowel cancer, and 12 days later my Aunt died following treatment for breast cancer.

I started chemotherapy in Mar 2001 and found the centre through a poster in the hospital, initially I attended a group which was a great opportunity to meet and share experiences with people who had or were going through similar situations and this was a great boost to my overall wellbeing.

Major surgery

In July 2001 I had major surgery, Then, in Sept 2001, I was readmitted to hospital acutely unwell, there followed a lengthy stay including two weeks in intensive care. I was discharged on Xmas Eve, with a very poor prognosis and among other medical issues, very restricted mobility.

In March 2002 I started to attend the Day Centre at Trinity Hospice one day a week. My Mum was also a day patient at the hospice but went on a different day. Trinity put in a referral for me with the Centre's Home Visiting Service, and I was very well matched with a befriender who was a fantastic support in the months just before and just after my Mum's death.

Improving health

My health, despite the predictions slowly improved, and I stopped going to Trinity as a day patient.

I still had regular contact with the Centre. Both the one-to-one complementary therapies, such as massage and reflexology, and the groups and classes - teaching valuable life skills like relaxation and meditation - have helped me to discover, adjust to, and thrive in my new 'normal'.



Claire Morgan

An old friend

So it continues – because Paul's Centre has been involved since the beginning, it is the one place I can go to for help and support without having to continually retell my story, which is long and complex. They understand the physical and emotional impact the diagnosis and subsequent treatments have had on me and how this can affect my decisions and choices in the present day. **The Centre is like an old friend that I can always turn to.**

Claire leads the User Involvement Forum at the Centre and has for the last five years provided invaluable voluntary help to the Centre's Information Service..