

THE WINSTON CHURCHILL MEMORIAL TRUST  
TRAVEL FELLOWSHIP REPORT

**CANCER SURVIVORSHIP:  
Current reality and future  
possibilities**



*Artwork by women cancer survivors, San Francisco*

**Report of Charlie Ewer-Smith, Churchill Fellow 2010**

Fellowship dates: September to November 2010 (8 weeks)

Theme: Treatment and rehabilitation of chronic conditions

Countries visited: Canada, United States of America, New Zealand & Australia

*'Cancer may leave your body, but it never leaves your life'*

**LIVESTRONG™**

*"I think being a cancer survivor is almost a badge of honour"*

- Mark, New Zealand

*"You never get back to the normal you had before cancer. It's a series of evolution – evolving as a different person"*

- Julie, New Zealand

*"You come out and everyone says, 'OK, you're OK now, and you can go back to your life', but you're completely different from how you went in. Physically, emotionally, you're a wreck; you just don't feel like the same person. Bloated, put on a lot of weight, can't walk properly, don't have any hair, extraordinarily tired. You know...they tell you it's over but it doesn't feel over"*

- Georgina

*"The day I was diagnosed with cancer was the day I started to live."*

- Lance Armstrong

## **BACKGROUND TO THE FELLOWSHIP**

### **Cancer Survivorship**

Cancer Survivorship can be defined as the 'process of living with, through, and beyond cancer. By this definition, cancer survivorship begins at diagnosis, and includes people who continue to have treatment either to reduce the risk of recurrence or manage chronic disease'. 'A cancer diagnosis may lead to a change in a person's priorities regarding relationships, career or lifestyle. Some survivors talk about appreciating life more and gaining a greater acceptance of self, and some survivors become anxious about their health and uncertain of how to cope with life after treatment. Survivorship is a unique journey for each person'. (<http://www.cancer.net/patient/Survivorship>)

Once active treatment is complete, the 'safety net' of regular and frequent contact with health care providers ends. At this time, survivors often report a sense of abandonment, a lack of emotional support, and an increase of anxiety around living with uncertainty, the fear of recurrence, and re-integrating a 'new normal' into life. In the UK, 61% of survivors feel unsupported in managing the emotional impact of cancer, 52% in managing practical aspects, 57% in managing the impact on their relationships, and 53% in understanding what services are available for them. (Macmillan, 2006). It has finally been acknowledged that health care follow up has traditionally been focussed on disease surveillance, but that it is now essential to develop effective interventions for people learning to live with the effects of cancer.

### **My hopes for the Fellowship**

I work as a Macmillan Occupational Therapist and am excited that, with new Department of Health strategies, cancer survivorship and rehabilitation are now firmly on the agenda. I left England in September 2010 looking forward to meeting with colleagues around the world in order to develop my own understanding and skills in this area, challenge myself to think in new ways, and to learn about developing survivorship interventions in a meaningful way. My focus was on adult survivors of cancer.

### **Itinerary**

**Toronto, Ontario, Canada:** The Odette Cancer Centre, Princess Margaret Hospital and Wellspring

**Austin, Texas, USA:** LIVESTRONG Headquarters

**Vancouver, British Columbia, Canada:** British Columbia Cancer Agency

**San Francisco, California, USA:** Helen Diller Comprehensive Cancer Centre and attendance at The California Breast Cancer Research Program Symposium

**Auckland, North Island, New Zealand:** Auckland Cancer Society and Auckland Oncology Unit

**Queenstown, South Island, New Zealand:** Interviews with survivors

**Brisbane, Queensland, Australia:** The Mater Hospital, Royal Brisbane and Womens Hospital and Princess Alexandra Hospital

**Melbourne, Victoria, Australia:** The Peter Mac Unit

## **THE FELLOWSHIP**

During the Fellowship, I met with over 100 health care professionals dedicated to improving the experience of cancer survivors and was also privileged to meet with many survivors who were willing to talk about their personal experiences with me. It would be impossible to keep this report concise if I relay all that I have learnt, so I hope to describe common themes, highlights and initiatives that particularly appealed to my objectives, and include reflections which I intend to share with colleagues on my return home.

### **Early Intervention: Psychological Support**

Each unit that I visited agreed that every patient should be screened for psychological distress, anxiety and depression early on, to help identify those at risk during their treatment and afterwards. Standardised screening tools were often used, with patients being directed to online, written and local resources, or referred to professionals if necessary. Patients should be screened for distress at entry into the system and then at known critical risk periods during and post treatment.

Auckland Cancer Society have introduced a series of free talks which can be accessed while patients are waiting for individual psychological support sessions; these offer intermediary support and provide coping strategies to use with immediate effect.

The Edmonton Assessment Scale (ESAS) is used at the Odette Cancer Centre. This is a patient directed tool which patients complete online at a kiosk in the out patient department prior to their clinic visit. Patients score themselves on a visual analogue scale with regard to the severity of the 9 common symptoms known to be experienced by cancer patients: pain, fatigue, nausea, depression, anxiety, drowsiness, appetite, wellbeing and shortness of breath. Evidence based algorithms and pathways to assist clinicians in responding to highlighted needs are being developed. ([www.cancercare.on.ca/toolbox](http://www.cancercare.on.ca/toolbox) contains all information on this tool). I gathered information on several other similar tools being used in other centres during my fellowship e.g PSSCAN, a tool developed at BC Cancer Agency.

Queensland Occupational Therapists and multi professional colleagues attend radiotherapy clinics and use multi professional screening tools to ensure early referrals for stress, sleep, claustrophobia , lymphoedema, cognitive, and pain management.

### **Education and Self Management**

Self management is defined as ‘tasks that a person needs to do in order to live well with their chronic condition/s; including gaining confidence to deal with medical, social and emotional management’ ([www.opimec.org](http://www.opimec.org)) All the survivorship initiatives I visited believed that effective self management and patient education should be regarded as essential elements of high quality modern health care. They were keen for patients to actively engage in their management and learn skills in self education, problem solving and self efficacy in order to gain confidence in doing so. The opimec website is a valuable resource in this area.

## **Telephone, online and technological interventions**

This area of intervention was more developed in those facilities covering larger geographical areas. I met information nurses who are available on the phone and online and write daily blogs; internet forums; telehealth; group teleconferencing; eportfolio learning; online educational programmes and seminars; an online cancer journey tool; the LIVESTRONG survivor care telephone helpline; and many IT based resources for professionals in larger countries who are separated by large distances. I have outlined 2 initiatives which I found particularly interesting:

- BC Canada's Clinical Psychologist has developed the website [www.cancerchatcanada.ca](http://www.cancerchatcanada.ca) providing online support groups and information, including resource manuals to accompany an online support group for young women recovering from cancer. The tool offers high quality professional psychological support for patients and families no matter where they live. Online support groups are low tech and cheap in comparison to video linking, and more intimate than teleconferencing. BC Cancer have also won awards for their website for children affected by cancer which allows children to create buddies for support, and receive key messages about cancer and learning coping strategies as they play. [www.cancerinmyfamily.ca](http://www.cancerinmyfamily.ca)
- Cyber Counselling: online counselling using an asynchronised approach, with the patient spending time writing a narrative to the therapist; it can be sent at any time which allows the patient to begin doing their own reflective work. The therapist then inserts comments or reflections into the narrative as though it was happening in the moment. This is an accessible, efficient way to deliver therapy which is more in depth than telephone counselling.

## **Survivorship Clinics**

I observed several clinics; patients were generally seen at these clinics between 6 months and 2 years of completion of active treatment.

Princess Margaret Hospital (PMH) was the only facility sending patients an appointment for the clinic at the time of diagnosis; the survivorship consult is seen to be as essential as any other appointment, as many patients may not think they need a survivorship consult, but then 'crash and burn' needlessly. This view was backed up by the patients I met – people who were competent and resourceful in their daily lives but admitted to feeling totally overwhelmed by their diagnosis, treatment options, navigating the system and accessing the help they needed. The PMH Breast Clinic was facilitated by a patient flow co-ordinator, with either the Social Worker or Occupational Therapists providing the intervention. It aims to promote self management, design interventions which minimise or reverse persistent and late effects of cancer and its treatment, and support healthy behaviour changes; thus engaging and empowering cancer survivors.

Patients are provided with a care plan document and follow up sessions as needed. PMH clinic is based on the City of Hope Quality of life Model (Beckman Research institute 2004) and run in

conjunction with the patient education department. Research has demonstrated that that this consult helps people put plans into place and set personally relevant goals.

### **Survivorship Care Plans**

The care plans I was shown contained any / all of the following:

1. Summary of cancer treatment history. Templates for this information are in use in much of the USA
2. Information on management of current and potential symptoms. Recommendations to report specific signs and symptoms if they are persistent.
3. Record of all known and potential late effects of treatment and timeframes in which they may occur. Advice on management.
4. Surveillance plan: both immediate and longer term.
5. Preventative care recommendations e.g need for counselling around alcohol consumption
6. Patient concerns e.g fertility, fatigue; and subsequent referrals to services
7. Psychosocial care; to include support systems already in situ
8. Patient priorities and recommendations for the future; including support services/groups

The plan is then sent to the patient, medical oncologist and other pertinent care providers. The American Society of Clinical Oncology have formatted templates which can be downloaded. The LIVESTRONG care plan is online and takes approximately 8 minutes for a patient to complete.

An Australian multi professional team have compiled a book on Survivorship which is given to patients at end of treatment.

### **Survivorship Programmes: a range of interventions**

Helping people cope with effects of cancer and its treatments requires a collection of varied, effective, high quality services and interventions offered in a co-ordinated fashion (a programmatic approach). I observed a wealth of innovative and creative approaches – including book clubs, author reading sessions, music workshops, peer support, buddy systems, drumming groups, quilting – too many types of interventions to list! Some themes included the following:-

Educational resources: Mini libraries, computers, pamphlets etc in clinic areas. Most units had several educational workshops running on topics such as fatigue, managing your cancer journey etc.

Supporting relationships: courses to support spouses of cancer patients, 1:1 peer counselling for couples, LIVESTRONG group to support siblings, support for children to learn age appropriate ways to talk about cancer in the family, teaching parents how to communicate with their children, sexuality workshops, group art therapy for children and families, LGBT support in San Francisco.

Living with cancer: education programmes in Victoria, managing your cancer journey classes (dealing with emotions , balancing life with cancer), finance management. A particular initiative was in San

Francisco, where medical interns help newly diagnosed patients develop a list of questions for their doctors, accompany them to appointments and make notes.

Symptom management: breast cancer education for pre-op patients, pain management, mindfulness stress reduction programme, brain fog programmes, fatigue clinics.

Exercise: Nordic pole walking, dragon boat racing, lebed method, nutrition classes.

Post treatment: life after cancer forums, post treatment classes, post treatment depression classes, from health care to self care (1:1 guided peer conversations), returning to work, vocational rehabilitation, fear of recurrence programme, young womens network group.

'Do you remember when' programme: resource files developed by Queensland OTs to enable people to reflect on their lives and record their journey; providing information on writing letters, appreciation books, life stories, scrapbooking and video messaging.

### **Outreach**

I observed many initiatives, but my favourite was the following: BC Cancer Agency employ a Chinese Social Worker who is developing an appropriate survivorship service for the Chinese community in Vancouver. She has developed a bilingual navigational resource guide, monthly support group (with 50 regular attendees) and Chinese Peer Navigator Programme which trains cancer survivor volunteers to provide information, assistance and emotional support in Chinese.

### **Research and Evidence Base**

During my trip it became clear that cancer survivorship research is becoming increasingly recognised as a valuable topic. All the centres in Canada and USA had research scientists dedicated to their survivorship programmes, meeting weekly to discuss research questions, enabling meaningful, progressive, researched and evidence based programmes to be facilitated. Key priorities were to involve clinical teams directly, raise awareness of research, identify and agree on worldwide priority topics, develop stronger collaborations across institutions and develop strong mechanisms for funding.

I met with teams working on amazing projects, including one dedicated to researching how modern technology can best be used to impact survivorship; and another considering survivorship needs of rural and remote communities.

### **Networking**

Everyone was keen to build an international consortia of major players to work together, share and standardise research based, locality relevant programmes within the field of survivorship. LIVESTRONG co-ordinate a Centre of Excellence Programme, and The Multi national Association for

Supportive Cancer Care is due its first conference on rehabilitation and survivorship in Athens in 2011. I was particularly impressed by the way in which LIVESTRONG utilise their unique branding to shine a spotlight on issues that require public attention in order to co-ordinate efforts professionally.

Research drives practice, researchers need to establish partnerships with clinicians in order to develop a common approach, and a global community is essential to enable rapid movements forward.

### **Example of a fully integrated process: University College of San Francisco**

1. Medical referral (all new breast cancer patients are referred)
2. Attendance at Group Visit – to learn about the programme and what to expect, give consent for data to be shared
3. Online Health History Questionnaire: part of an integrated survey system. Several standardised assessments are included. Parameters are set around certain questions which immediately trigger referrals, for example if someone scores highly for distress, the system will alert the Social Worker.
4. On completion, a report with the following information is completed: personal summary, red flags, disease history, treatments, social history, referrals and guidelines for the patient, medications, family history, health scores, areas for consideration, and clinical notes. The patient receives a patient friendly version, and the family doctor receives a version containing relevant advice regarding surveillance and information on the survivorship programme.
5. Nurse Practitioner appointment to go through the survey and compile a personal plan
6. Attendance of Survivorship Group: presentation, question and answer session, provision of the ACTIVE (After Cancer treatment information for Vitality and Empowerment) Manual and information on the Survivorship Programme
7. Attendance of programmes
8. Periodic follow up surveys
9. Ongoing care and support provided by Nurse Practitioner

### **Personal Reflections**

I was overwhelmed by the readiness of colleagues overseas to extend their hospitality and time to me; many are keen to work collaboratively in the future, and I feel incredibly honoured to have met with so many dedicated, enthusiastic and truly inspiring people. I was also humbled by those people living with cancer who allowed me to share some of their experiences. I will return home with a wealth of new information, friendships, partnerships and resources. It will take me forever to be able to share and disseminate all that I have learnt, but a few of my reflections on ending the fellowship are as follows:-

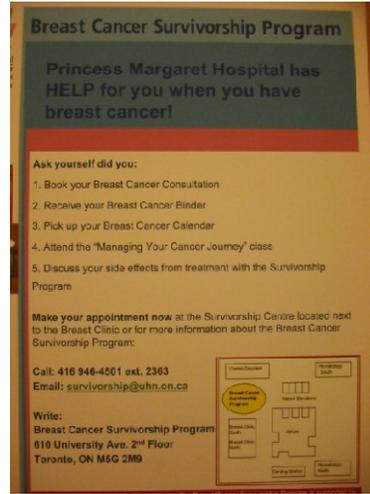
- Small, high quality changes add up
- It is essential to prepare patients for the end of their treatment phase – good quality cancer care requires the provision of a cancer survivorship plan, and it is our duty to provide this to our patients
- Our aim should be to reduce distress and enable self management where possible; education around self efficacy should commence at the start of treatment
- Creative and varied interventions, from various partners who continually check out the value of their programmes with their users, are essential. Experimentation is important!!
- Specific survivorship research programmes and knowledge management will ensure effective and meaningful interventions. It is time to seamlessly integrate clinical care and research, and to develop collaborative databases
- Collaboration between clinicians and researchers should be utilised to work on a global scale; working as a global community has the potential to change attitudes around living with cancer
- There may be resistance from other professionals to survivorship work; demonstrating evaluations of survivorship programmes can be used to build trust and respect
- Our patients deserve to receive interventions in high quality environments and receive well researched and produced information – its time to stop using photocopied leaflets!
- We need to educate our wider communities about the issues of surviving cancer; recruit facilitators from local communities and raise the public awareness of what is, and what is not, helpful to people living after cancer.

### **Acknowledgement and Thanks**

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View from Vancouvers Cancer Centre



Breast cancer Survivorship programme, PMH. Toronto



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Survivorship Unit, Toronto



Scott Secord, Manager, Survivorship Programme, Toronto



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