Navigating the system at Concord Cancer Centre
Concord Cancer Centre

Concord Hospital: tertiary teaching hospital – University of Sydney

Cancer Services:

• Medical Oncology, Haematology, Surgery, Palliative Care,
• Radiation Oncology
• Survivorship Centre

» clinical leadership with multi-disciplinary services
» cancer screening
» fast access to treatment
» strong research collaborations – e.g. ANZAC Institute, Asbestos Diseases Research Institute, SuRG, individual researchers/groups
CCC- Care across the cancer continuum

- Diagnosis
- Treatment
- Survivorship
- End of life care
Who is Who in the CCC Zoo?

Medical cancer specialists:
correctly diagnose and assess the stage of your cancer, recommend and implement a treatment plan and monitor your progress, manage the symptoms and side effects of cancer and treatment.

- Surgeon
- Medical Oncologist: solid tumours, chemotherapy
- Haematologist: blood tumours, chemotherapy
- Radiation Oncologist: radiotherapy
- Palliative Care specialist: symptom control, end of life care
Role of Oncology Clinical Nurse Consultants

• Coordinate Care during chemotherapy
• Provide assistance with symptom management
• Liaise with Medical Team
Oncology Clinical Nurse Consultants

• Once need for chemotherapy identified
  – Make appointment for pre chemotherapy session
  – Arrange scans and or procedures prior to treatment as required
  – Consult with allied health team regarding your individual requirements

• If not requiring chemotherapy can assist with access to clinic in timely fashion or advice as required
Oncology Clinical Nurse Consultants

• Work with nursing colleagues
  – Breast Care Nurses
  – Colorectal Care Coordinator
  – Upper GI Nurse Consultant
  – Palliative Care Nurse Consultant
Care Coordinator

- Advocate for the patient
- Participate in multidisciplinary team meetings
- Identify opportunities for patients to participate in clinical trials/research studies
- Facilitate support groups
Care Co-ordinator (CC)

- Assistance navigating health system
- Scheduling of timely appointments
- Ensuring comprehensive recording of patient information in health records
- Provision of emotional support
- Families reported CC provided advocacy, support, education and monitoring of patients progress
Care Coordinator

Facilitate quality and continuity of care for patients:

• Provide patient centred care
• Triage patients to determine areas of need
• Provision of education and information tailored to patients needs
• Role of care coordinator varies according to the area they are employed, type of cancer
• Aim to provide a more streamlined and coordinated care for patients
Care Coordinator

• Be aware of consultations, treatment plans and outcomes

• Assistance with navigating the health care system

• Liaise with health professionals across different treatment/support areas to help streamline patients care

• Facilitate scheduling of appointments
Care Coordinator

- Early identification of potential/actual problems post hospital stay

- Provide a central point of contact for patients and clinicians

- Participate and work collaboratively within a multidisciplinary team
Care Coordinator

• Advocate for the patient

• Participate in multidisciplinary team meetings

• Identify opportunities for patients to participate in clinical trials/research studies

• Facilitate support groups
Improving Patient Care

Cancer Institute NSW (2011) – Evaluation of Cancer Care Coordinator - Feedback: (Patients, Families and Clinicians)

• Care well coordinated including managing co-existing problems

• Consistently informed about cancer diagnosis and treatment pathway

• Education about procedures/self care

• Reinforcement of information from other health providers
Improving Patient Care

- Assistance navigating health system
- Scheduling of timely appointments
- Ensuring comprehensive recording of patient information in health records
- Provision of emotional support
- Families reported CC provided advocacy, support, education and monitoring of patients progress
Other specialist cancer nurses

• Haematology – Lynda Wignall

• Breast - Lorraine Roache and Cole Deguchi

• Gastro-intestinal – Beth Whittaker

• Genitourinary - Caroline Wildbore
Concord Cancer Centre Psychology Services

Jessica Medd
Alex Withers
Sue Butler
About 1 in 3 cancer patients will experience psychological difficulties at some time following their diagnosis.

Information Privacy

At Concord Cancer Centre we work as part of a multi-disciplinary team with your doctors, nurses and allied health professionals.

As part of NSW Health privacy policy our notes from your appointments are kept in your general medical file. This does mean that other staff involved in your care have access to our notes and the records we keep about our contact with you. In addition, we may send out important information about your care to your GP.

If you have any concerns about us sharing personal information please let us know, so we can discuss it with you further.

Your Clinical Psychologist is:  
____________________________________

You can contact them on:  
____________________________________

Your next appointment is:  
____________________________________

Contact us for an appointment on:  
Psychology Department  9767 6550
Urology Department  9767 6410

Other useful contacts:  
Oncology Department  9767 7093
Haematology  9767 5769
Main Switchboard  9767 5000

Concord Repatriation General Hospital
Hospital Road
CONCORD  NSW 2139

Support with your cancer experience

Cancer is often associated with a variety of physical, emotional, role, spiritual, psychological, and self-identity changes. These changes can affect the person who has cancer, their family or carers. Often, there are sudden changes in a person’s circumstances, making it more difficult for them to cope.

Family members and others close to you are also under a great deal of stress and may have no one to turn to for support.

A Clinical Psychologist is a person who can help assess and treat any mental health issues you may be experiencing.

A Clinical Psychologist can help you with:

- Adjusting to the cancer diagnosis
- Coping with physical changes in your body
- Stress and worry
- Sleep problems
- Anxiety (worry about your health and treatment, fear of needles, fear of your cancer coming back)
- Feeling low or depressed
- Grief and loss including loss of identity or your role in life
- Coping with physical pain, nausea or fatigue associated with your cancer and treatment
- Changes to your sexual desire and response
- Conflict in relationships

Who can attend?

Anyone who has had a cancer diagnosis and their family or carers can attend.

How much will it cost?

The service is free for you to see a Clinical Psychologist at Concord Hospital.

Other members of the team:

Your Social Worker provides counselling, advocacy and information about a large range of social and community services.

A Psychiatrist is a medical doctor who can help with medication, assessments for capacity to make decisions, reports for insurance and severe mental health problems (e.g. hallucinations).

A Pastoral Care Worker can offer a listening ear and supportive presence and explore how your illness interacts with your faith.
How can Social Work help you?

- We offer a service to both inpatients and outpatients and their families and carers
- Our service is free and confidential and includes
  - Counselling and support
  - Assistance accessing practical support
  - Referral to and information about community resources
  - Information and health education
  - Help in navigating the ‘system’
  - Help in talking to children about cancer
How do I see a Social Worker?

• You can refer yourself
  – contact the Social Work Department – 9767 6680
  – ask your doctor or nursing staff to contact us

• Your doctor or nursing staff may refer you if they feel you need some practical or emotional support
Occupational Therapy

- Focus: maximum independent functioning
- Aim: assist individuals to do the things that they want to or need to do in their everyday lives.
  - changing the activity (e.g., simplifying the steps of the activity)
  - changing the environment (e.g., enhancing supports available, incorporating reminders / prompts)
  - skills training

Occupational therapists provide a range of services including:
- Assessments of functional skills (e.g., cooking), including functional cognition (problem solving skills and adaptability)
- Planning for discharge from inpatient units
- Modification of home / Equipment hire

Lymphodema – Jane Maher
Provide dietary advice regarding to healthy eating during and after anti-cancer treatment

Screen and assess patients’ nutritional status and provide support to those who are malnourished or at risk of becoming malnourished

Provide education and expert advice to colleagues in relation to patient care, or nutritional related issues

Provide strategies to assist patients with symptoms and treatment side effects that affect oral intake

Conduct nutrition related research

Dietitian
Accredited Exercise Physiologist (AEP)

4-year university degree
Specialise in exercise therapy and lifestyle interventions for the prevention and management of chronic disease, injury and disability.
Can help with:
- Improve recovery following cancer treatment
- Improve general health and wellbeing
- Overcome persisting pain caused by injury
- Weight management
- Lifestyle education to help manage health conditions
Physiotherapist

• Assess, diagnose, treat and work to prevent disease and disability through physical means
• Experts in movement and function - APA
• Can help with:
  – Recovery from injury
  – Reduce pain and stiffness
  – Increase mobility
  – Prevent further injury
What is a Cancer Survivor

Varying definitions:

- From diagnosis
- After completing primary treatment
- Disease-free for a certain number of years
- Alive 5+ years after diagnosis

In Australia: ~ 750,000 cancer survivors -expected to increase ~3%/year
Why are survivorship issues important?

Traditionally focus has been on acute treatment
→ follow-up/surveillance on detection of cancer recurrence
› experience of *surviving* cancer has been poorly understood

→ shift to recognise importance of **QUANTITY** and **QUALITY** of survival
Life after cancer diagnosis and treatment...

- assumption that survivors will return “back to normal” following their treatment
- reality is life may be vastly different to the life before cancer
- may be more difficult than during the active treatment phase
Patient quotes:

“I felt such a sense of security when I was going through treatment... you get so used to going day after day... then all of a sudden, it’s over. You felt safe while you were going there, and now that you’re not going there anymore you feel like something is going to happen.”

“Then all of a sudden, like six months later (post-treatment) is when it finally hit me, and I don’t think people were prepared for it because I’ve been so strong. People looked at me and physically I’m fine and I can do everything again, I mean it took me six months before it hit me.”
“Lost in Translation”
US Institute of Medicine report

- Landmark report
- Post treatment phase is a distinct phase that requires increased attention by clinicians
- Psychosocial and support needs of many survivors/their caregivers and families are currently not met
- Poor coordination of care
- Oncology care providers commonly underestimate distress in patients
Medical Issues in Survivorship

Increased risk of cancer:
- Recurrence
- Second cancer – same type, 2°to cancer Rx, - genetic or other susceptibility

Long term side effects (dependent on treatment):
- Infertility
- Cardiac dysfunction
- Thyroid problems
- Impaired pulmonary function
- Damage to nerves
- Osteoporosis
Cancer survivors report issues across a wide range of areas:

- **Physical** e.g. fatigue, fertility, pain
- **Cognitive** e.g. memory, learning, concentration
- **Emotional** e.g. fear of recurrence, uncertainty re future
- **Financial** e.g. medical costs, difficulty recommencing employment
- **Social** e.g. changed relationships with partner / family / friends
- **Existential** e.g. re-evaluating values & goals, changed outlook on life

(Boyes, Hodgkinson et al, 2009)
Survivorship: unmet needs

• Many cancer survivors are able to overcome these issues in time, but some continue to have unmet needs:
  • 30% with 5+ unmet needs (Armes et al, 2009)
  • 54% with 1+ unmet need (Hodgkinson et al, 2007)
  • 38% with 1+“significant” unmet need (Soothill et al, 2001)

• The greatest unmet needs in these studies are psychosocial, rather than physical aspects of cancer survivorship.
  • Existential issues most highly endorsed:
    “help with concerns about the cancer coming back”
Survivorship: Top *unmet* needs (n=259)

<table>
<thead>
<tr>
<th>Concern</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concerns about the cancer coming back</td>
<td>61</td>
<td>23.6</td>
</tr>
<tr>
<td>Accessible hospital parking</td>
<td>47</td>
<td>18.1</td>
</tr>
<tr>
<td>Up to date information</td>
<td>46</td>
<td>17.8</td>
</tr>
<tr>
<td>Understandable information</td>
<td>45</td>
<td>17.4</td>
</tr>
<tr>
<td>Doctors talk to each other/complementary therapy/ongoing case manager</td>
<td>41</td>
<td>15.8</td>
</tr>
<tr>
<td>Others acknowledging the impact</td>
<td>39</td>
<td>15.1</td>
</tr>
<tr>
<td>Survivor expectations/information for others/reduce stress in my life</td>
<td>38</td>
<td>14.7</td>
</tr>
</tbody>
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*K Hodgkinson et al (2007)*
Sydney Survivorship Centre
Programmes
The Sydney Survivorship Centre (SCC) at Concord Cancer Centre

Opened September 2013
Aim: provide holistic care for adult survivors

Major Components:
• Survivorship Clinic
• Weight management clinic
• Courses with focus on healthy lifestyle
• Education – public forums
• Support groups
• The Cottage: Resource / Drop in facility
• Survivorship gym
• Research
• Bridge back to community facilities
Sydney Survivorship Clinic Model: 1\textsuperscript{st} visit

- Dietitian
- Oncologist/Haematologist
- Exercise physiologist
- Psychologist
- Cancer nurse

Cancer survivor
Initial Visit:

1. Questionnaires
2. Treatment & Survivorship Care Plan
3. Assessment: medical & psychosocial side effects/late effects, disease status
4. Education of healthy lifestyle and ways to maintain their health e.g. diet, exercise, stress, smoking
5. Package of information: DVD, booklet
6. Referrals as appropriate: eg. social worker, genetics, endocrine
Weight Management Clinic

Background:
› Known lifestyle risk factors associated with cancer risk and recurrence
   - Obesity
   - Physical inactivity
   - Smoking
   - Inadequate fruit and vegetable intake
› 62% of patients attending Survivorship clinic are overweight or obese
› 42% meeting current guidelines for physical activity
Weight Management Program

Referral Pathway & Eligible Patients:
Localised disease – completed primary cancer treatment

Prerequisites:
› Survivorship Clinic
› Participated in ENRICH
› BMI >=25kg/m²
Weight Management Program Clinic

Medical Oncologist, Dietitian, Exercise Physiologist (EP)

Time points: Week 0, Week 6 then 3, 6, 12, 18 and 24 months

Intervention:

<table>
<thead>
<tr>
<th>Week</th>
<th>0-6</th>
<th>7-12</th>
<th>13-26</th>
<th>26-52</th>
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</thead>
<tbody>
<tr>
<td>Supervised PA sessions</td>
<td>2/week</td>
<td>2/week</td>
<td>2/week</td>
<td>1/week (optional)</td>
</tr>
<tr>
<td>Dietary sessions</td>
<td>1/week</td>
<td>1/fortnight</td>
<td>1/month</td>
<td>-</td>
</tr>
<tr>
<td>Behaviour Support</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
Lifestyle Intervention

- 6 X 2 hour per week group sessions
- Co-facilitated by Dietitian and Exercise Physiologist

Dietitian sessions:
- better food choices; understand food labels, cooking methods and menu ideas to make healthier meals.

Exercise sessions:
- Practical sessions: resistance
- Walking
- Link into community groups at conclusion

Survivorship Courses
Survivorship Courses

Medical Qigong

Gentle Yoga
Courses

Mindfulness

Music Therapy
Support Groups

Peer support...

Sharing the journey together.
You are invited to the following free presentations on the second Monday of each month:

9th February @ 5.00-6.30pm
Navigating the system at Concord Cancer Centre
  ✓ Speakers from the Centre

9th March @ 5.00-6.30pm
Post treatment concerns for cancer survivors: a focus on breast cancer
  ✓ Dr Belinda Kiely, Jane Mayer, A/Professor Harvey Stern

13th April @ 5.00-6.30pm
Complementary and alternative medicines for cancer patients
  ✓ Professor Andrew McLachlan, Michael Dash, Gwenda Bate, Jessica Zhang, Alan Lem

11th May @ 5.00-6.30pm
Side effects from cancer and cancer treatment
  ✓ A/Professor Janette Vardy, Sue Butler, Dr Haryana Dhillon, Dr Prunella Blinman

13th July @ 5.00-6.00pm
Cancer & nutrition / Intimacy & enhancing relationships after a cancer diagnosis
  ✓ Dr Cindy Tan and Kim Hobbs

10th August @ 5.00-6.00pm
What happens after treatment for bowel cancer
  ✓ Professor Marc Gladman and Sonia Khatri

14th September @ 5.00-6.00pm
Living with the fear of cancer recurrence / Physical activity for people with cancer
  ✓ Sue Butler and Jane Turner

12th October @ 5.00-6.00pm
Understanding genetic risk for cancer / Caring for the carer
  ✓ Speakers to be confirmed

9th November @ 5.00-6.00pm
Laughter Wellness Workshop – Living with hope
  ✓ Sharon Gambrill

Venue: Concord Hospital Medical Education Centre – Lecture Theatre 1, Ground Floor
(entrance off Hospital Rd through Gate 3)
Light refreshments will be served from 4.30pm
Survivorship Gym
Survivorship Research Group (SuRG)  
Centre for Medical Psychology & Evidence-based Decision-making

Survivorship Issues:

› Cognitive Function:
  - Animal model
  - Incidence
  - Duration
  - Risk Factors
  - Mechanisms
  - Treatment

› Physical Activity:
  - Impact on disease free survival in colon cancer
  - Impact on fatigue in people with lung cancer

› Symptom Control:
  - Fatigue
  - Pain
  - Sleep
  - Patient perceptions of side effects of chemotherapy
  - Sexuality
"I wanted a perfect ending. Now I’ve learned the hard way that some poems don’t rhyme and some stories don’t have a clear beginning, middle and end. Life is about not knowing, having to change, taking the moment and making the best of it without knowing what’s going to happen next."

Gildna Radner