

Children's Cancer Centre news

Issue 4 December 2008

making news...

2 • Look Good... Feel Better for Teens

- Sibling days

3 • James' story • Jacqui's story • Tips for VCE or VCAL

- Health care
cards for 16+
year olds
- 2009 diary

4 • CCCPAG news • LARCH news • CBTA news • Activities 2009 • Teen camps • Parent library • Tell us about CCC

Adolescents and Young Adults in the Children's Cancer Centres

A review of new patients diagnosed at The Royal Children's Hospital (RCH) over the past three years showed that 118 were between the ages of 12 and 18. This is approximately 25% of all new patients treated at the Children's Cancer Centres (CCC) – so on average, there may be 3 adolescents or young adults in the CCC each day!

With gathering momentum and much enthusiasm, a multidisciplinary team has come together to focus on optimising care for Adolescents and Young Adults (AYA) being treated and cared for within the CCC at the RCH and MMC. The Paediatric Integrated Cancer Service (PICS) AYA subcommittee chaired by CCC oncologist Dr. Lisa Orme is meeting monthly to work on a broad range of AYA issues.

The committee is focussing on:

- Education and professional development for staff working with AYA in the oncology setting
- Ideas to provide AYA-friendly care for both inpatients and outpatients
- Improvement of existing adolescent facilities
- Planning services and facilities for the new RCH
- Investigating opportunities for clinical research collaboration with the Centre for Adolescent Health and onTrac@petermac
- Opportunities for consumer and support group input and collaboration
- Provision of resources on adolescent oncology for staff, and also a range of resources and literature for adolescents, young adults, their parents and family.

The AYA subcommittee will form strong recommendations on strengthening services available to AYA being managed at the RCH and MMC CCC. This is an extremely exciting and important area of work, with much still to be done!

- To make sure we develop things that are important to the AYA, we need your input! We want your thoughts and ideas about your care, about our existing facilities and what we should or could have in new facilities too!

Here are some examples of what you have told us so far:

"I really love the teen's room. I think that it is a great place for outpatients to hang out and have fun. But I think that it should be inside the ward because we are not usually allowed to go in when we are an inpatient. I also think you should get a bigger room and more X-box® games." (RCH)

"We would love some space in the day unit which is just for us!" (MMC)

Teens, want to tell us more? Great! Then please fill out the tear off section on the back page of this newsletter and pop it in the box at the RCH or MMC CCC or you can give it to the nurse coordinator at Peter Mac. Thanks!



Hayley resting at RCH

Christmas message from A/Prof David Ashley – Director CCC RCH

My time away on sabbatical over the past few months was a great privilege and allowed me to observe how others care for children with cancer in a similar, large and complex centre. There are many lessons I was able to glean and hopefully some of these we can apply here in Victoria. Whilst we can certainly make improvements and are far from perfect, throughout my time away, I also became increasingly aware that our staff here are unparalleled in their dedication and empathy for our patients and families. I would particularly like to thank Dr Peter Downie for doing such a great job as Acting Director in my absence.

The forthcoming year is likely to face us with new and ongoing challenges; finances are certainly not going to get any easier! This will mean it is even more important that we all work together as a team to continue to deliver improvements in care, education and research that we have seen over the past few years.

I wish everyone a safe and happy holiday season and look forward to the New Year ahead.



The Royal Children's
Hospital Melbourne

Murdoch Childrens
Research Institute
Healthier Kids. Healthier Future.

Peter Mac
EXCELLENCE INNOVATION COMPASSION

Paediatric Integrated
Cancer Service
A statewide cancer service for children

Southern Health

Look Good...Feel Better for Teens

The Look Good...Feel Better for Teens program has been specifically developed for teenagers between the ages of 12 and 20 who are or have been treated for cancer. The program provides peer support for teenage patients and an opportunity to share their experiences of cancer, to learn about a range of coping strategies and to have fun! Among other things, it helps participants deal with some of the physical changes that may occur as a result of treatment and is based on the idea that "looking good" will help them "feel better".

The RCH CCC held a workshop in June with nine girls attending. A social worker and music therapist facilitated discussion about different responses to cancer, the impact of treatment and coping techniques. This discussion was used to form lyrics to a song chosen by the group. A copy of the song written on the day was later recorded and given to every participant. The workshop

- also included a skin and make up consultation, where everyone was taught how to manage aspects of their appearance affected by their cancer treatment.
- Participants were given skin care tips and a kit of products to take home. Finally, a representative from Celebrity Wigs provided participants with an opportunity to experiment with a range of wigs, hats and bandanas in a safe environment. Feedback from the program was very positive, with participants commenting particularly on the value of meeting other girls who could understand what they were going through.

- The Monash Medical Centre (MMC) CCC held a workshop in August for adolescent girls currently undergoing treatment, and their sisters or close girlfriends (if they didn't have a sister to share with) were invited. The afternoon session started out very quietly as the girls did not know each other, but a short time later the room was filled with chatter,

- laughter and serious moments as the girls experimented with makeup and skin care products. The group jelled so well that when it was time to leave and their mothers were waiting to pick them up they continued to chat and share their experiences. For these girls it was the first opportunity they had to meet other girls of the same age experiencing the same issues. For their sisters or girlfriends it was an opportunity to see that they were not alone in trying to support their sibling – they were included in their sister/friends journey and had some fun at the same time!

- The Look Good...Feel Better workshops are coordinated by the social work department and run at the CCC at RCH and MMC. Participation is free. Please contact the social work department for more information.

Sibling days

The social work team at RCH and MMC, assisted by the nursing and medical teams, run sibling days for the brothers and sisters of patients at the CCC. The last day was held on 30th September at RCH and was attended by twelve children ranging from 5 to 15 years. In the morning Dr Pratiti spoke about cancer and answered lots of interesting questions. They then went on a behind the scenes tour of the oncology pharmacy and saw where the chemo is made up. They also went to pathology and saw where blood is kept for transfusions and where the blood tests go to for analysis. The children were able to look down a microscope at a blood sample. They also visited outpatients and had their height and weight measured (if they wanted to) and their blood pressure checked but no finger pricks! A nurse then spoke to the children about central lines and finished off with some fun with syringes and water. The afternoon was spent talking and working in smaller groups. The children were able to discuss their experiences through various creative activities to get to know other siblings like themselves.

Comments from the siblings included what they learnt:

"what my brother has and how it can be fixed"; "stuff about blood"; "how things work and what is inside my body"; "I learnt that a lot of people felt what I did".

Many thanks to KOALA Kids who provided a show bag of goodies to each child and who sponsored the yummy lunch. Sibling days will be held in school holidays in 2009. If you would like more information please contact your social worker.



James' story



Hello! I'm James.

On Boxing Day last year, in the happy time before cancer, I bought my first yacht, Coronet, which is a Gwen 12. I only got to sail it once, and then I was diagnosed with cancer in January this year aged 15. I'm 16 now and have had surgery and four rounds of chemotherapy. I am currently studying year 10 and will soon be starting VCE.

When I started chemo at The Royal Children's Hospital I came in every three weeks for my usual 'stint' of five to seven days. The Scottish pipe band would ring me up to see how I was getting on. I've been in the pipe band as a drummer for seven years and was asked to go to Scotland for the first time and play with another band at the Tattoo – but unfortunately I got sick. I'm also in my school's senior band and orchestra and have been asked to join the Melbourne Youth Orchestra too! (Yes, I'm a muso!)

The worst things about getting cancer aren't shingles or losing my hair but losing my memory. But there are more good things that came from cancer – I've started to do all the things I've always wanted to do like join the Australian Navy Cadets, live healthier (eat healthier, ride my bike to things and do more exercise), get out more with my friends and smile more. Oh and have more fun!

Jacqui's story

Going in for chemo is always tough and something I will never get used to. Having said that, there could be no better place to come to than the Children's Cancer Centre at Monash Medical Centre. It's comforting to come in and always see a smiling, familiar face behind the desk. Being small and intimate, I have been able to get to know the staff members. I am so amazed at how dedicated everyone is who works there. The nurses are such a great help. They are really calming and easy to relate to but most importantly, they listen. It feels like they are there because they want to be and not because they have to be. Sometimes it's hard to find people to talk to who can relate to what I'm going through, but the nurses always have time for me and try to understand what I'm going through.

Sometimes it's hard being one of the older patients because there is no one else my age that I can relate to or just chat with. As most of the facilities are geared towards the younger kids, it can also get a bit boring sometimes especially when waiting to receive chemo or see a doctor. Still, the treatment room has a really great atmosphere and I'm always comfortable sitting on the reclining chairs! I'm really grateful to be part of the Children's Cancer Centre.

Tips for VCE or VCAL

- Completing VCE or VCAL while undergoing treatment for cancer may seem unrealistic, but with correct advice, consistent support and guidance from school, it is achievable.
- For those of you who have just completed your VCE or VCAL, congratulations! If you are about to begin, this really is an exciting and yes, daunting time. Here are few tips to help you get started:
- Firstly, organise a meeting with your VCE/VCAL Coordinator to discuss your options:
 - Review the VCE/VCAL handbook, particularly Chapter 11: Special Consideration. <http://www.vcaa.vic.edu.au/schooladmin/handbook/2009/index.html>
 - Information may also be sought from the Victorian Curriculum and Assessment Authority (VCAA). <http://www.vcaa.vic.edu.au>
- During the meeting:
 - Carefully consider the VCE/VCAL requirements and special provision criteria.
 - Complete your application for appropriate special provision.
 - Discuss possible tertiary options. Investigate the Victorian Tertiary Admissions Centre (VTAC) entry criteria VTAC: <http://www.vtac.edu.au> and, particularly the Special Entry Access Scheme (SEAS): <http://www.vtac.edu.au/seas/>
 - If you're studying VCAL it is important that a pathways plan is established with your VCAL coordinator and/or careers counsellor. Discuss this in your meeting too.

Finally, make sure you are receiving accurate information from an informed source – not just friends.

If you would like to chat more about VCE or VCAL please don't hesitate to call or send an email at anytime to:

Nicole Edwards, Education Consultant, RCH Education Institute, (03) 9322 5112, Email: nicole.edwards@rch.org.au

Health care cards for 16+ year olds

Are you about to turn 16? Did your parent or carer previously have a Carer Allowance Health Care Card (under 16) for you? If so, you may be eligible for a Health Care Card if you are a full-time student and under 26 years old. You will need to complete an "application for a health care card for former recipients of a Carer Allowance Health Care Card" in your own name to continue getting the benefits of the health care card. Call Centrelink on 13 2717 or go to the website www.centrelink.gov.au where the application form is available. For assistance, see the social worker at the CCC. Please note, the application DOES NOT require a signature from your doctor and unfortunately while the health care card may be transferred once you turn 16, the allowance itself cannot.

2009 diary – now available!

The 2009 parent diary is now available and features contact numbers and maps for the RCH CCC, MMC CCC and Peter Mac.

School holidays are shaded throughout the calendar and there is plenty of space to record appointments, notes and blood test results. Ask any member of the CCC for your copy of the diary.

