



Report from the Children's Cancer Centre - August 2007

'Eating well during chemotherapy' - Jodie Bartle

Accredited Practising Dietitian CCC RCH

Eating well is important for all children, especially when they are having treatments like chemotherapy. Many of the drugs used can affect how your child eats for a period of time and this may cause parents some concern. Some of the side effects of chemotherapy that affect your child's eating may include sore mouth, taste changes, poor appetite, and nausea.

General dietary recommendations for adults such as low saturated fat, high fruit and vegetable intake to reduce 'long term' cancer risk are inappropriate for children who are on treatment. Often children rely on foods high in saturated fat such as meat and dairy because they are energy and nutrient dense, and are needed in their diet to achieve adequate growth and nutrient intakes.

Try to offer your child small meals often, say 3 small meals with a snack in between. Try not to force your child to eat, offer encouragement and try to sit with your child while eating, let them see you eat something too. Try not to worry if they don't eat much, remember that there is another meal or snack coming in a few hours.

It is best not to give your child their favourite foods too often when they are feeling unwell, or change the way the whole family eats to suit the child having treatment. Children can often develop a dislike for food they eat while feeling very unwell. This means that these foods may no longer be eaten much, even when the child feels better. On the other hand, by trying to bribe your child with sweets and treats, you may find your child will only eat or demand these foods later and want less of their usual healthy foods.

Try to offer familiar foods you know your child likes the same as the rest of the family is eating.

Although your child may seem more 'fussy' at times, continue to offer a variety of foods, even if they sometimes may be refused. Try to stick with your usual routines, but be flexible, as your child may not always eat the same way depending on their appetite. Mealtimes may take a little longer at times, but try not to let them drag on past about 30-40 minutes.

It's a good idea to have individual portions of meals you know your child likes in the freezer, this saves you preparing endless meals. Take away foods and sweets can be included occasionally when the rest of the family has them.

While there are no special foods that must be eaten or avoided, some of the side effects of chemotherapy may alter eating habits. Below are suggestions on how to deal with some of the side effects most commonly experienced by children:

Loss of appetite

This can be common, so take advantage of every opportunity to eat well when appetite is good. Ideas to improve appetite include

- Offer smaller serves of food, but more often say 5-6 times a day.
- Keep nutritious snacks handy so your child has easy access to them
- Keep meal times relaxed with no arguments over food.
- Try not to fill up on low nutrient foods such as cordials, soft drinks and lollies as there will be less room for other more energy and nutrient dense foods.
- Offer cold food with less smell e.g. interesting sandwiches such as cream cheese, fresh chicken or roast meats, peanut butter, banana or jam

Give your child some praise when they eat, even if it is a small amount.

Sore mouth or mouth ulcers

- Encourage soft foods with sauces and gravies e.g. minced beef and gravy with mashed vegetables, scrambled eggs, soups
- Breakfast cereals with lots of milk
- Soft desserts such as milky puddings, custards and mousse
- Milkshakes to help wash foods down
- Try to avoid acid or rough foods like citrus fruits and toast.
- Try foods cold or room temperature rather than hot

Nausea

It is very difficult to eat when nauseous. No special diet will treat or solve this problem, but it is important that children do not go for too long without eating. Never force your child to eat, you can make up for lost energy when your child feels better. Medication is often prescribed for severe nausea. Try to offer:

- Small serves of food more frequently to avoid getting too full or too empty.
- Cold foods with little smell
- Encourage your child to eat and sip drinks slowly
- Meals in a well ventilated room to clear the smell of foods away
- Snacks of salty dry biscuits and fizzy drinks may be better tolerated
- Fluids are important, so offer these regularly to sip
- Don't offer favourite foods at this time.

High energy eating:

If your child is managing small amounts of food only, encourage them to eat foods high in energy, and include foods high in protein. This way they will get the same amount of nourishment in a smaller amount of food.

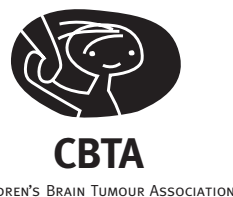
Food high in energy or protein include

- Milk: Use full fat varieties in milk shakes, on cereals, in puddings, to make up soups, mash into potato. Make white or cheese sauce for pasta and vegetables.
- Yoghurt: Can be used as an in-between meal snack. Add to milk drinks or to fruits and desserts.
- Cheese: Grate cheese into soups, mashed vegetables, sauces and omelettes, sprinkle over vegetables, mix into tinned soups, baked beans or spaghetti.

Offer cheese on toast, or cheese and dry biscuits for a snack.

- Meat, chicken and fish: All meats are suitable. Leave the fat on meat, and serve with a sauce or gravy. Add some oil to the cooking for extra energy.

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Finally "Our Story" Board is up once again. Thanks to everyone for their patience. Stories will be rotated on the board and we are happy to hear from any of our patients who want to write about their journey. It is a great way to share your stories and to give other families lots of encouragement. If you wish to attached photos) with your story please feel free to do so.

"What's on Where Board" will soon be displayed in the O/P waiting area. It will consist of a Victorian Map with each region colour coded. It will have an area to display information about the different auxiliary meetings and events as well as other social get togethers for the families of the CCC - stay tuned it will be here very soon.

Thanks to all the families and friends for the continued donation of up to date magazines they are really appreciated by those families who use the area frequently.

'Eating well during chemotherapy' continued from page 1

- Oils, Margarine, butter, cream and mayonnaise: Are a useful way to increase the energy content of low kilojoule foods. Melt over vegetables and spread more thickly on toast, bread and dry biscuits. Add cream to desserts, sauces and breakfast cereals.
- Supplements: Foods such as Sustagen* and Polyjoule* are often used for children who have poor intake and appetite. Your Dietitian will be able to help you decide if these are needed.

Good food hygiene

When having chemotherapy, your child's ability to fight infections is reduced. Some bacteria can also cause foods to spoil and cause gastroenteritis, which results in problems such as nausea, vomiting and diarrhoea. Some common sense precautions will help to avoid this. These guidelines are particularly important when your child's blood count is low (neutropenic).

- Wash your hands before preparing any food
- Fruits and vegetables should always be washed before eating
- Store raw and cooked foods in different sections of the fridge
- Keep raw meats away from all other foods
- Use a separate chopping board for raw meats
- Defrost and cook foods thoroughly particularly meats
- Do not keep hot foods at room temperature. Keep hot foods hot in the oven and cold foods cold in the fridge.

The dendritic cell immunotherapy clinical trials have opened and we have three patients enrolled to date. We aim to enroll 18 patients over the next 3 years and at this pace will easily achieve that goal. The new generation anti-tumour vaccines will be manufactured in the new state of the art GMP (Good Manufacturing Practice) Clean Room Facility housed at the RCH in conjunction with the Cell Therapeutics Facility.

We will be utilizing this great facility to produce high quality clinical grade cellular products to treat children with advanced malignancies. We will educate the patients own immune cells to attack their own tumors by manipulating them in the laboratory. This process will yield at least 6 vaccine doses which the patient will receive biweekly as an injection. We and others have shown previously that this type of immunotherapy has little to no

- Check 'use by' and 'sell by' dates of foods

Eating during low counts (neutropenia)

When your child's blood count falls very low, there are some foods that it may be worth eliminating due to the higher risk of bacterial contamination. These include

- Take-away foods, particularly if unsure of how long they have been cooked, or if not kept piping hot.
- Never use unpasteurised dairy products
- Soft cheeses such as blue vein, ricotta, camembert and brie and pate
- Fresh fruits that are very difficult to wash such as berries
- Soft serve ice-cream
- Bought pre-prepared salads such as coleslaw and potato salad
- Uncooked/fermented deli meats such as salami and hams
- Uncooked herbs or herbal supplements

Alternative or fad diets

Many diets and dietary supplements are promoted as a treatment for cancer. Often these lack the essential nutrients for normal growth and good health and may be expensive, hard to follow and very impractical. Some may even be dangerous. It is essential that you discuss any changes to diet, or plans to take a food, vitamin or mineral supplement with your doctor.

side effects and can produce significant clinical responses in some patients. The promise of the potential of immunotherapy to treat solid pediatric tumors continues to inspire researchers to pursue and improve these novel therapies.

Dr. Denise Caruso

Monash Medical Centre news

Recent changes to the provision of general anaesthesia at MMC has resulted in an improved service to children and their families. Since January this year, the GA list for procedures such as LP's and BMA's has been held within the CCC unit. Children are able to arrive around 8.00am, wait in the familiar environment of the unit, move into the procedure room with their parents and with staff they know. Following the procedure and recovery, its back to the waiting room in the unit and then home before 12.00. This is a radical improvement from the 7 or 8hr duration with the old system. This change has been viewed as such a success within MMC that the paediatric rehabilitation team is currently trialling a GA list for their children requiring administration of Botulinum toxin-A (Botox) in our unit on a Thursday afternoon. It is great to see that a change in practice initiated for the children attending the CCC has been expanded to improve the care provided to children with other medical conditions.

**Katrina Carey,
Clinical Nurse Coordinator, Monash**

Staff changes across the sites

Social Work Team

Lorraine Jenner (social work) has left Monash Medical Centre to pursue greener pastures. Thank you Lorraine for all your great work firstly at the RCH and in more recent times at MMMC. Lorraine has been replaced by Jennifer Ellis. Jennifer was welcomed to the CCC in late June.

The Social Work Team at RCH would also like to welcome two new staff members to our team, Lily Obradovic and Debbie Kertesz. Lily and Debbie are both experienced social workers who come to us with a wide range of expertise and skill. They joined the CCC in early September. The Social Work Team at RCH look forward to being fully staffed again after a number of months of staff shortages. CCC RCH Social Work Team members at the RCH now are: Saskia Hampele, Lily Obradovic, Debbie Kertesz, Helen Stewart, Liz Wynne and Nicole Tokatlian (Team Leader) with Jennifer being the CCC Social Worker at MMMC.

Medical

Dr Peter Downie will return to clinical duties in the first week of October from his Sabbatical leave. A/Prof David Ashley is then taking Sabbatical leave for the October, November and December 2007. Dr Steve Keogh who will be covering both doctors throughout this period and we are very pleased to welcome Steve back. Some of our families may remember Dr Leanne Super. Leanne was a Fellow at the RCH back in 2001. Leanne returned to us a consultant working across the RCH and MMC sites in early August. Welcome back Leanne. Dr Mary Dwyer has joined the paediatric radiation oncology team at Peter Mac. She joins Dr Greg Wheeler in providing the medical care to the children requiring radiation therapy. Dr Dr. Pratiti Bandopadhyay will return to the RCH until Jan (short for January) and Dr Paul Wood has commenced at MMC for the same period. Dr Marty Campbell remains at the RCH.

Nursing Staff

Katrina Carey, the CNC at MMC is due to leave in late August to pursue parental duties. Recruitment has commenced and we will advise her replacement soon.

Children's Cancer Centre Sibling Day -Royal Children's Hospital

The Children's Cancer Centre Social Work Team held a "Sibling Day" at the Royal Children Hospital on 6 July. Seven brothers and sisters of children with cancer attended the day. They ranged in age from 8-14 years. Jeni Moodie, nurse coordinator, answered the children's questions about cancer, including what treatments are used, how people get cancer and what they can do to help their siblings during this time. The children also got a 'behind the scenes' experience with a tour to pathology where they learnt about different cells and the process of what happens when their sibling's blood is being tested. They also got the opportunity to experience first hand some of the processes that their siblings would have to undertake when coming to an outpatients appointment.

After lunch, the social work team ran activities where the children got the opportunity to talk about what it

has been like for them to have a brother or sister with cancer and share some the many emotions that they were experiencing as well as talk about ways to manage those emotions. As part of the afternoon session, the children worked on a collage that they either made for themselves about their understanding of cancer or some chose create a collage to give to their brother and sister as a token of love and support.

Staff members received positive feedback from the children about how enjoyable the day was and that they had learnt so much about cancer that they did not know before. One of the participants told a staff member, "I wish it was sibling day every day".

Sibling days are held both at Monash Medical Centre and the Royal Children's Hospital throughout the year. You can talk to you social worker if you want to find out more about this program.



L.A.R.C.H. NEWS

Leukaemia Auxiliary Royal Children's Hospital

LARCH Meeting Dates for 07/08

Tuesday 18th September 2007 (extra meeting)
Tuesday 20th November 2007
Tuesday 19th February 2008
Tuesday 20th May 2008
Tuesday 19th August 2008 (AGM)

Meetings commence at 6.00 pm and will be held in the meeting room at Ronald McDonald House, 22 Gatehouse Street, Parkville (opposite the hospital), unless otherwise indicated. Parking is available on Gatehouse Street, Flemington Road and the two side streets either side of Ronald McDonald House.

Pease join us at our next meeting to be part of a positive future that sees LARCH continue raising funds for vital research.

LARCH Social Calendar

Our next event will be held on Thursday 11 October, at 12.00 noon, at the Kingdom Chinese Restaurant, Tooronga Village, East Hawthorn. Please let Chrissie know by Monday 8 October, on 9827 0072 or 0402 848 535 or email chrissie@charlyblue.com, if you are able to join us. Please feel free to bring a friend or two! The more the merrier. The cost is \$20, payable on arrival to Chrissie, with \$5 per head going back to LARCH. The cost includes entrée and three mains (buffet style), rice, tea and water.

LARCH Bags and Shaker Tins

We now have LARCH shaker tins available to place in your local club, workplace or just at home to collect your spare change. Please contact Chris McRae on 9331 2373, if you would like a tin.

The popular range of RCH tote bags, retailing at \$2.00 each are a very important and regular part of our fundraising. These bags are available for placement (with a tin to facilitate payment) at one of your local shops, workplace, school, etc. Please contact Christine Boulter on 03 9827 0072 for further information.

LARCH on eBay

Some very exciting news! Paula Lienert has set up an online shop to sell pre-loved designer children's clothing on eBay. We are looking for pre loved designer (only) label kids clothes (Fredbare, OshKosh, Esprit, Gumboots, Scooter, etc) that are clean and in good condition that we can sell on eBay - all proceeds to LARCH.

If you can help out with donations of clothing please contact Paula on 0411 106 948.

LARCH Stall Talk

The stalls in the foyer of RCH have become progressively better each time as the new co coordinator, Christine Boulter, learns the tricks of the trade. Christine McRae and June Box are regular helpers with the running of the stalls on the day, along with Noelene and Lil who pop back for old time's sake. Please find following the remaining dates for this year.

2007

Monday 24 September 2007
Friday 5 October 2007
Friday 26 October - Cup Day Stall
Thursday 29 November - St Andy's Stall
Friday 7 December
Friday 21 December - Christmas Stall

2008 First Thursday Of Every Month

7th February, 6th March, 3rd April, 1st May, 5th June, 3rd July, 7th August, 4th September, 2nd October, 6th November, 4th December and 18th December.

Donations for the stalls are always needed and gratefully accepted. Knitted items for babies always sell well, as do items such as aprons, book bags, cotton boxer shorts, cotton or cotton interlock PJ pants, all sizes including adults, summer hats, little girls dresses to aged 6, fairy dresses and skirts, and satin wizard capes.

More helpers are always needed on the stalls. If you would like to help, we have loosely defined two 'shifts' consisting of:

Shift 1

7.00 am to 10.00 am to help with stall set up.

Shift 2

10.00 am to 2:30 pm to help with selling and pack up.

These times are extremely flexible to suit you. Even one hour of your time will help. If you are able to help on any of the above dates please contact Chrissie Boulter - phone - 03 9827 0072, mobile - 0402 848 535, email - chrissie@charlyblue.com.

For pick up or delivery of your donations or any queries you may have regarding our stalls or if you would like to assist on any of the above dates please contact Christine Boulter on the above numbers.

I would like to thank all the people who have made kind donations to our stall over the past few months since I have taken over the stall organisation. Cheryl Kline, who regularly leaves a parcel for us at the auxiliary office, all the lady knitters who leave garments at the auxiliary office and also the second hand children's clothing which has been donated to put on our EBAY stall (run by Paula Lienert). A special thanks to Vicky Kogioumtzis and the members from the CBTA who have donated product to the our stall.

LARCH would like to acknowledge the generosity of the following individuals & organisations for their support.

- Yering Station Gallery • Knot Just Wooden Toys, Garfield • Pretty Mermaids Boutique
- Town & Country Gallery Yarragon
- Family and Friends of Emilia Lofaro
- Friends of LARCH • S Richey • B West
- S McGregor • J Hudson • Una Thompson
- J & N Briscoe • Mirboo North Homestyle
- Dragonfly Beads • Nar Nar Goon Bingo
- Lal and Rene of Mirboo North

LARCH Raffles

Nestle has very kindly donated four wonderful hampers to us - these will be raffled at the Children's Cancer Centre Outpatients reception desk over the next couple of months. Tickets are \$2.00 each. If you are in the hospital and wish to purchase a ticket, please drop into the Outpatients Reception desk on the 6th floor.

Vale

LARCH are saddened to hear of the death of Mrs Una Thompson of Colac who died suddenly on 31 July this year. Una has been knitting top quality toys (many people will remember Noddy and Big Ears and the many other toys and Christmas goods) for Noelene to sell on our Stalls for about 15-20 years. Una had a wonderful team of helpers in Colac who have been of great support to LARCH over a long period of time.

I will miss the chats with her.

Noelene Hammond.

Donate to LARCH

LARCH is committed to raising funds specifically for the Children's Cancer Centre. 100% of donations are directed toward research and care of children with cancer and their families at the Royal Children's Hospital in Melbourne. All donations over \$2.00 are tax deductible.

Donations to LARCH can be made by sending a cheque, money order or credit card details using our form downloaded from the LARCH website and sent by mail to:

L.A.R.C.H.
C/o Auxiliaries Office
Royal Children's Hospital
Flemington Road
Parkville Vic 3052

Contact Us

President: Claudia McCarthy

Treasurer: Christine McRae

Vice President: Mario Lopreiato

Secretary: Emma Bridgeman

Stalls Coordinator: Christine Boulter
ph 03 9827 0072 mob 0402 848 535
email - chrissie@charlyblue.com

Phone: 9539 1169

Internet: www.rch.org.au/larch

e-mail: larch@iprimus.com.au

LARCH Lindenderry Luncheon 2007

The fourth bi-annual LARCH Lindenderry Lunch was held at Red Hill on Sunday June 17. Despite modest weather those attending presented with cheerful countenances. This is not hard to do when faced with the prospect of excellent Lindenderry food and the usual magnificent Yering Station wines. And importantly Hawthorn had handed Carlton a belting on the previous Friday evening.

Proceedings opened with the mystery auction, which rewarded Mrs Sue Angliss with an An dex investment chart, a bottle of Heathcote Estate Shiraz and most fittingly a copy of Mary Ellis' History of Gardening in Victoria.

Question Time followed and produced a fifty fifty result. Questions were obviously not hard enough!

The traditional State of the Union address followed and managed to incorporate presidential sleeping habits, the web addresses of Hilary Clinton and Robert Mugabe and of course the introduction of our new LARCH President Claudia McCarthy who, whilst issuing a warm welcome to the assembled host, was too reserved to discuss her sleeping habits with strangers. Instead she issued a timely reminder as to the rationale for LARCH's existence: The funding of cancer research and the provision of financial and other support to families having children diagnosed with cancer.

It was a great pleasure to have our guest speaker Professor Henry Ekert reminisce about the history of certain significant donations and the contribution of the earlier mentioned Mary Ellis to the introduction of bone marrow rescues to cancer treatment. A recently produced Cancer Centre film was appreciated by all.

Much nonsense took place during the silent auction with certain persons making it difficult to find a bargain. However, all went well and indeed went to a good cause.

Our thanks to the usual suspects for their generosity and working support. The question remains however will we do it again.



Former LARCH President and Comic MC, Mervyll Reid at Lindenderry Red Hill

The CBTA committee would like to offer their sincere condolences to Geoff and Val Walters and their family on the recent passing of their courageous daughter Leanne.

The CBTA continue to meet, support one another and fundraise. Gift wrapping under the CBTA banner has taken off in great strides thanks to Kelley and her two sisters Bec and Kate. The last weekend was held for Father's Day and the girls tell us it was a good weekend. The girls will be back again at Angus and Robertson in Greensborough in the weekends leading up to Christmas. All the proceeds from these gift wrapping days go straight to the CBTA funds. It is a great way to fundraise and also a sensational way to raise public awareness about Childhood Brain Tumours and Spinal Cord Tumours. CBTA would like to thank the staff at Angus and Robertson for their continued support.

LARCH ART

*Yering Station Gallery, 38 Melba Highway, Yarra Glen
Mel ref. 275,B6*

Alternate Routes - Painting by Penelope Long and Karen Standke
Innerscapes and Nothingness - Photography by Andrew May
4 August - 22 October



In Penelope Long's third exhibition at Yering Station Art Gallery, she references art history, street graffiti and matter sourced from the detritus of her studio. Through the luscious medium of oils Penelope explores new ways in which different types of beauty can be united and harmonised.

Penelope Long is represented by Nellie Castan Gallery, Melbourne.



Andrew May started practicing in the visual arts in 1998 as a result of his travels as a musician through northern Europe in mid 1997. On returning to Melbourne, Andrew began working in the field of photography and large scale drawing. Andrew is a self taught photographer who manipulates shells of inner rooms or dark glimpses of the city to capture moments of solitude and reflect his inner mindscape.




Born in Munich, Germany, Karen Standke grew up in Ehrwald, Tyrol, Austria.

Admission is free and commission from sales will be donated to LARCH, Leukaemia Auxiliary of the Royal Children's Hospital, Melbourne.

For any further information, images or interviews:
Wed or Thurs - Amanda Ruck T - 03 9730 0100 M - 0418 389 964 E - artgallery@yering.com

Opening hours: 10.00 am - 5.00 pm weekdays and 10.00 am - 6.00 pm weekends and public holidays.

LARCH again wishes to acknowledge the generous support of Yering Station through their donation of all commissions on artworks sold during their exhibitions.



BrainChild news

CHILDREN'S BRAIN TUMOUR ASSOCIATION

Our next educational night will be on September 4th with Dr. Margaret Zacharrin, Endocrinologist giving us a presentation of the varied issues facing our young children.

Diary Date for the CBTA members, their family and friends Saturday October 13th. This is the evening of the annual CBTA fundraising dinner. It promises to be a great evening. If any member are able to obtain items for the silent auction for the night can they please contact me Rosemary Sandalis on 0412 216 443. Tickets for this night

are \$80 and please contact Rosemary or Mary McGowan on 9345 4855. Flyers for this event will be available this week

The CBTA. would like to congratulate Sue Manson and her Auxiliary Office staff on their recent AGM - Celebrating 85 years of Auxiliary work at the RCH. Keep up the wonderful work everyone.

**Rosemary Sandalis
President**