August 2014 *Volume 8: Issue 2*

HSANZ
Haematology Society of
Australia and New Zealand

Inside:

Plus much more…!

Newsletter design and publishing:
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www.haa2014.com

19-22nd October 2014, Perth WA Early Bird registration closes: 12th Sept 2014

HAA 2014 @ the Perth Convention & Entertainment Centre is only 3 months away. The nurse's stream, run over 3 exciting days, has been finalised and abstracts have been submitted.

Please have a look online for the latest conference updates.

- A focus on blood and bone marrow transplantation; GVHD, managing the 'older' patient; donor selection.
- Back by popular demand – an interdisciplinary panel based complex case discussion focussing on a transplant patient.
- Paediatric/adolescent & young adult sessions will showcase the work Perth is doing in this area of haematology nursing.

- Pragmatic approach to managing myeloma – unravelling this ever complex blood cancer; updates in research & practice.
- Nursing 'How To…' workshops focusing on a range of current topics including nurse lead clinics and nursing audit and research.

Pre – HAA 2014 Haematology Education Day
Saturday 18th October 2014
St John of GOD Subiaco Hospital

HSANZ Nurses Group WA will be hosting an education day for nurses and allied health professionals @ SJOG Subi conference centre. The event is supported by the WA Cancer & Palliative Care Network and the WA Cancer Council.

This day is *focused on educating graduate nurses, nurses with limited haematology experience, practice & clinic nurses* or anyone interested in updating their knowledge about their patients from a haematology perspective.

An email with further information will be sent soon. If you require further information please contact me at: cassi.lawrence@health.wa.gov.au

Care After Treatment in Haematological Cancer Patients: A National Nurse Practice Survey

Participate to improve care and enter a lucky draw to WIN an IPAD

It is an absolute honour for our research team to work with the HSANZ Nurse Group to distribute this important survey study. As nurses working in the haematology and BMT setting, we know that patients with haematological malignancy have substantial care needs after completion of their treatment. Nurses, as the largest cancer care professional workforce, are well-placed to provide appropriate care to these patients.

This national survey of cancer nurses' practice will be administered using SurveyMonkey®. Through your participation, we aim to (i) identify acute cancer care nurses' attitudes, confidence levels, and current practices in relation to post-treatment survivorship care for patients with haematological malignancies; and (ii) examine nurses' perspectives of factors that influence the provision of survivorship care. All questionnaires will be anonymous. Our ultimate goal is to design a nurse-led multidisciplinary intervention program to improve the quality of life in our patients. Please feel free to forward the email invitation to any colleague who you believe can be involved in this important undertaking.
Participate today by clicking here: https://www.surveymonkey.com/s/prosurv

A word or two from the President…

Can you believe this is the *'last word'* you will hear from me!

Having been one of the founding members of this incredible group, it has been my pleasure and honour to have had the opportunity to support and more recently, lead the HSANZ Nurses Group and witness its evolution over the past 8 years. As a group we have all achieved so much in a relatively short period of time. Our core business has been to grow our membership and to support haematology nurse education with the hosting of a robust 3 day nursing program within HAA each year and hosting 20-30 events per year. Our newsletter has grown from a few pages to a regular 40 page e-newsletter and remains one of the best formats to communicate with our membership. We've been able to support members to attend HAA each year through a grants program in some States and most excitedly for me as an ageing haematology nurse (!) we've been able to support the next generation of haematology nurses to attend HAA, through the recent Bayer sponsorships.

This bumper edition of our newsletter is jam packed with news, updates, events and educational items. We hear from some of our recent grant winners who attended World Federation of Haemophilia in Melbourne; important changes to how you need to document CPD / hours of learning; a great summary of audit and questionnaire design; a beautiful piece from Leukaemia and Blood Cancer Foundation (Rebecca Weeks) on the benefits of Therapeutic Journaling' and much more.

> For those members who may have inadvertently forgotten to pay your subscription charges –please make the effort to do so with head office. You can contact the office on Tel: 02 9256 5456 or hsanz@hsanz.org.au to check your status or arrange to make a payment. The nurses group is funded by associate nurse subscriptions so we are all affected by a missed payment. Watch out for a reminder in your inbox soon if you've missed a payment.

As my term as President of the nurses group finishes at the end of HAA 2014 in Perth I look forward to remaining involved as an active member and attending HAA as a participant. I will be working with the soon to be formed Myeloma Special Interest Group (M-SIG), currently forming within the HSANZ NG, more on that in the next edition of this newsletter. Don't forget – we are all part of haematology nursing in Australia and New Zealand and it takes effort and active participation from each one of us to drive our profession forward to achieve more for our patients. Please do consider getting more heavily involved in your regional groups, submit work for HAA and get in touch if you have something to say or share.

I now confidently hand over the leadership to Jenelle Peppin and the National Council and encourage you all to continue to be as welcoming and supportive to them as you have been to me over the years.
See you in Perth.

Tracy King

President HSANZ NG

Tracy.king@sswahs.nsw.gov.au

Ronald McDonald® Learning Program

Ronald McDonald House Charities Australia

Education Liaison at Sydney Children's Hospital

Connectedness, hope, future, advocacy, education, support, recognition, team.

Carolyn Armstrong

In September 2013 I took up the position of Education Liaison Coordinator at Sydney Children's Hospital Randwick. The role is the result of a joint partnership between the Kids Cancer Centre and the Ronald McDonald Learning Program. Sydney Children's Hospital and Ronald McDonald House Charities have enjoyed a long association with each other as the Ronald McDonald House has been situated on the Randwick hospital campus for the last 23 years.

About me:

I have a background in both health and education. I spent over ten years working in health as an Enrolled Nurse. Whilst my work as a nurse covered many different fields, my time was primarily spent in the area of Palliative Care. In 1998 I retrained as a teacher and taught in government and independent schools in NSW in various capacities over the next ten years. This unique skill set has given me specific insights into both health and education.

So what is Education Liaison?

The purpose of the Liaison position is to provide coordination and continuity of education for children and young people diagnosed with cancer and blood disorders. In a nutshell, the role aims to keep kids **connected** both socially and academically when they are absent from school due to illness. The role acts as the point of contact with schools on behalf of families who often have no physical time or emotional resources to do so themselves. I work with children from Preschool to Year 12. The position is a diverse one, requiring liaising with multiple stakeholders across organisations and departments to ensure a holistic team approach to the educational care of the individual.

The role:

Advocacy on behalf of students forms a major component of the Liaison role. All too often students who are absent for any length of time from school sadly become a case of 'out of sight, out of mind'. My role is to keep children and young people supported and linked to their school and peers. I communicate with and advise schools about the educational needs of the individual child as well as strategies to maintain contact. Assistance may be given to schools in how to adapt curriculum content, write modified learning programs as well as co-planning back to school agreements with all stakeholders. This collaboration with schools enables them, in turn, to support their student more fully with appropriate learning strategies. In addition the role provides coordination of special provision applications for examination support and university entry concessions to reduce the amount of educational disadvantage the student has to encounter.

Education Liaison requires close collaboration with Oncologists, Haematologists, Social Workers, Psychologists and CNC's. I attend weekly meetings with the Multi-Disciplinary Paediatric and AYA Oncology Team, Hospital School and any other relevant agency to communicate the educational issues and needs of the child.

Monkey in my Chair

I provide and establish in schools this wonderful initiative, which aims to maintain a physical presence in the classroom with the use of a large soft toy monkey that sits in the place of the absent child. This enables the students to keep their classmate in the forefront of their minds. The child in hospital keeps a small version of the Monkey as a reminder of their home school and school friends.

The kit also contains a beautiful storybook, which explains in simple terms, why their classmate is absent, a teacher companion guide, a journal, photo album and other items. Photos and stories can be taken and collected sent to the child to reassure them that they remain part of the class despite their absence. The Monkey is well received and loved by both the child and the school community.

What happens after treatment?

As a student nears the end of their treatment or is ready to return to school, they are referred to the Ronald McDonald Learning Program for tuition if there are learning gaps that may have arisen during prolonged absences. The Learning Program can provide comprehensive educational assessment, a year of one-on-one tutoring sessions with a qualified teacher and speech and occupational therapy if required. Since 1998, the Ronald McDonald Learning Program has provided more than 6000 students with a much needed boost to their confidence and self-esteem and it will support over 900 students from Preschool to Year 12 each week across Australia. It is fully funded by Ronald McDonald House Charities. Schools are also referred to our EdMed Program. This accredited professional learning module explores the educational effect chronic illness can have and ensures all staff have a better understanding of the student returning to school.

It has been a privilege to be part of such an amazing and much needed service. It gives a voice to families facing the most difficult of times. Children who miss school due to illness should receive the education that all children have access to. I hope one day to see the inclusion of an Education Liaison position in every paediatric hospital across Australia.

Carolyn can be contacted on carolyna@rmhwestmead.org.au

Further information can be found at: www.learningprogram.rmhc.org.au

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leukaemia & blood cancer new zealand
our mission is to care, our vision is to cure

Therapeutic Journaling

Rebecca Weeks,
Support Services Coordinator Leukaemia & Blood Cancer New Zealand

'when you look at a person, any person, remember everyone has a story. Everyone has gone through something that has changed them' – Author unknown

A growing body of literature demonstrates that writing about traumatic, stressful or emotional events can result in improvements in physical and psychological health. Articles published in the Journal of Advanced Nursing (2013) and Journal of Clinical Oncology (2014) conclude that expressive writing is an easily implemented approach for patients diagnosed with breast and renal cell cancers to improve quality of life and physical functioning and reduce cancer-related symptoms. This effect may occur through short term improvements in cognitive processing.

There are many reasons why someone may choose to use journaling as a supportive tool and different methods of journaling will suit different people. Encouraging patients and family members affected by a blood cancer to journal can be a simple and effective way to help them cope with the emotional impact of their diagnosis and treatment. Some people may find benefit in writing descriptively about their life, capturing details of everyday experiences which may feel mundane at the time, but which can often serve as precious memories for them or their family in the future.

Another option is to write about treatment which may include recording big events such as stem cells being returned on transplant day, but could also include day-to-day moments such as who was the nurse working with them, or what pumps, tubes or infusions were in situ on a given day. This information can create a record of their/their relative's journey through treatment. Recording and documenting practical information about medical treatment, for example tracking blood results or keeping a list of questions for the healthcare team, can increase feelings of empowerment and control. If a patient is experiencing symptoms, which are having a negative impact on quality of life, they may find it useful to keep a symptom dairy. Keeping a record of symptoms/side-effects (e.g. pain, fatigue, nausea etc.) can help identify patterns, which may improve coping and can be helpful when discussing symptoms management with the healthcare team.

'How are you feeling today'?

Whilst commentary style writing is appropriate for some people, others may like to write more reflectively about how they are coping emotionally. Taking time to write about reactions and feelings about diagnosis and treatment can help reduce stress and manage worries, fears and doubts. Seeing thoughts written down can validate them (even if they are not shared with anyone) and help put them into perspective. The act of writing gives people time to sort through uncomfortable thoughts or complex issues and can help with the decision-making process if needed. Journaling can encourage people to reflect on what a cancer diagnosis means to them and their family and can facilitate the answering of some existential questions. During difficult times, encouraging people to re-read older journal entries can serve as a visual record of how they coped previously and perhaps offer strength and confidence.

'…a life changing experience, with a duality of positive and negative aspects…' Doyle, 2008

Journaling can also be used to record positive thoughts, affirmations, or quotes that may encourage or reassure. Some people are able to identify positive situations or events that have unfolded as a result of a diagnosis and keeping a gratitude diary is one way of focusing attention on positive aspects of life.

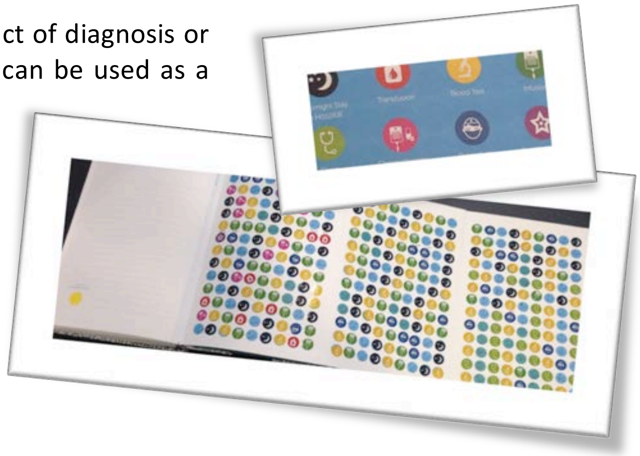
'For the meaning of life differs from man to man, from day to day and from hour to hour. What matters, therefore, in not the meaning of life in general but rather the specific meaning of a person's life at a given moment' – Frankl, 1963

Other suggestions of journaling may be to draw or scrapbook feelings. Writing a story, poem, song or letter are also good ways to explore emotions. Regular writing can be a great way to help manage the effects of 'chemo brain' and may also be beneficial for people who struggle to sleep. One strategy to reduce mental activity at bedtime is to set aside a 'thinking time' earlier in the evening, during which things that are worrying are written down. Other people find writing first thing in the morning clears their mind for the day. Some people prefer to keep their journal private, whilst others may share it with family and friends or use it as a tool to assist with communicating with family or healthcare professionals.

Leukaemia and Blood Cancer New Zealand (LBC) journal and sticker diary

To encourage people to use writing as a way of coping with the impact of diagnosis or treatment, LBC has created a journal and sticker diary. The stickers can be used as a quick and easy way to record the treatment journey.

The mum of a young boy diagnosed with Chronic Granulomatous Disease who had a cord transplant says 'it's easy to forget what's happened or information you need to know when there is so much coming at you. It was amazing to have a daily record during the transplant process to record everything we needed to know. The stickers were so special for him too. They mark every test and every procedure. He may not understand it yet, but he will when he gets older.' His sticker diary is photographed below.



Another family found the journal and sticker diary useful when a 12 year old boy wasn't able to visit his mum during her bone marrow transplant. She would keep him involved with her treatment by texting him each time she had chemo, transfusion or a procedure etc and he would use the stickers to record it. He also kept a diary of what he was doing so he could remember to tell her what he had been doing while she was in hospital.

If you would like more information about the LBC journal please contact: Rebecca Rebecca@leukaemia.org.nz

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Doyle, N. (2008) Cancer Survivorship: evolutionary concept analysis. *Journal of Advanced Nursing* 62(4) 499-509.

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Milbury, K., Spelman, A., Wood, C., Matin, SF., Tannir, N., Jonasch, E., Pisters, L., Wei, Q., Cohen, L. (2014) Randomized Controlled Trial of Expressive Writing for Patients With Renal Cell Carcinoma. *Journal of Clinical Oncology*. 32(7) 663-670.

Lifehouse LivingRoom

Improving the wellbeing of cancer patients with evidence-based complementary therapy

Michael Marthick, *Exercise Physiologist, LivingRoom, Chris O'Brien Lifehouse*

Michael Marthick is an accredited exercise physiologist at Chris O'Brien Lifehouse and an Allied Health professional. As part of the team of complementary therapists in the Lifehouse LivingRoom, Michael works in collaboration with healthcare teams (including oncologists/specialists, nurses and dietitians) to support oncology patients and help them manage symptoms such as fatigue, diminished strength and reduced quality of life as well as running rehabilitation programs for blood and bone marrow transplant patients. He also coordinates a BMT Rehabilitation program at Lifehouse.

Research suggests that while 65% of Australian cancer patients seek to complement their treatment with some type of integrative medicine or therapy (Oh et al 2010), most don't consult with their doctor or medical staff about the full range of available options (Gillett et al 2012). This is one of the reasons a complementary therapy centre was a major part of our patient offering at Chris O'Brien Lifehouse, back when Lifehouse itself was just a vision.

The Lifehouse LivingRoom is the home of complementary therapies at Chris O'Brien Lifehouse. It's a purpose-built facility on the ground floor of our integrated cancer centre, offering a range of evidence-based complementary therapies to Lifehouse patients and their carers, as well as clients from the general community and cancer patients from other hospitals who have been referred. As LivingRoom practitioners, we are all accredited/certified (as appropriate) within our specific fields and have a special interest and expertise in treating oncology patients.

The therapies on offer through the LivingRoom include:

Exercise Physiology

Qigong

Reflexology

Tai chi

Oncology massage

Acupuncture

Mindfulness

Yoga

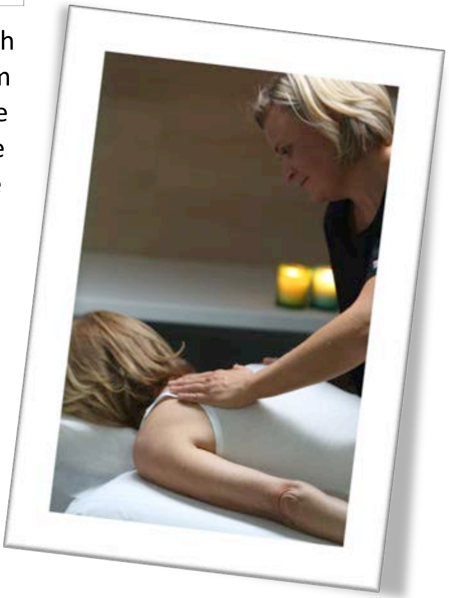
Nutrition/ Dietetics

Clinical Psychology

Encouraging access to evidence-based supportive complementary therapies, as an adjunct offering alongside clinical cancer treatments, empowers patients to choose a care program that promotes overall health and wellbeing, not just eradication of the disease. Indeed, when the late Professor Chris O'Brien was diagnosed and received treatment for a malignant brain tumour (glioblastoma multiforme), he turned to some of these therapies, including acupuncture and meditation, and sought advice on his diet to ease the side effects of chemotherapy and help manage his symptoms. Even in terminal cases, complementary care can improve quality of life and help patients manage symptoms and feelings of anxiety in a compassionate way.

Though research into the effects of complementary therapies on patients with haematological cancers specifically is growing, many clinical studies have reported that integrative therapies have a positive impact on general symptoms of cancer: these general symptoms are commonly experienced by haematological cancer patients and therefore we may extrapolate the study results into the haematological patient population. For instance, many of the therapies we offer in the LivingRoom (acupuncture, reflexology, massage, exercise physiology, meditation and nutrition) have been shown to reduce "fatigue, nausea, stress, decreased appetite, bone and joint pain, fevers and sweats" (Wesa & Cassileth 2010).

As well as cancer symptoms, many of the side effects associated with chemotherapy and radiation therapy to treat haematological cancers can be minimised by the application of complementary treatments such as massage, acupuncture, meditation, exercise physiology and nutritional intervention.



For example, a number of clinical studies have shown that treatment with acupuncture can relieve cancer symptoms and treatment side effects or keep them from getting worse. Emerging research supports the use of acupuncture to improve xerostomia in patients undergoing radiation therapy (Garcia et al 2009) and to ease chemo-induced peripheral neuropathy (Wong & Sagar 2006), which can maximise the delivery of chemotherapy and therefore improve treatment outcomes.

Similarly, a number of studies funded by the National Cancer Institute and the National Institutes of Health in the USA indicate that reflexology shows promise in reducing pain, enhancing relaxation and sleep and that it specifically complements cancer care. Research also indicates that massage and reflexology treatments "have a very favourable risk–benefit ratio and very low risk of adverse side effects" (Wesa & Cassileth 2010).

When it comes to exercise physiology and nutrition, a good level of physical fitness and a lifestyle that includes regular exercise and a sensible diet can significantly reduce some treatment side effects and may even prolong survival.

Recently, scientific evidence has significantly changed our ideas about the relationship between physical activity, rest and cancer-related fatigue. Aerobic exercise has been proposed as a method for improving fatigue. An aerobic training program can break the vicious circle of lack of exercise, impaired performance and easy fatigability. Burgeoning literature on the effects of exercise on cancer rehabilitation shows promising results particularly for breast cancer patients, on whom the majority of research has been conducted (Carslon et al, 2006).

Even gentle exercise can improve wellbeing in cancer patients and lead to diminished symptoms and side effects, as revealed by a three-week controlled study focusing on bone marrow transplant patients. The in-patients involved in the study walked for 12 minutes daily and reported a reduction in levels of distress and depression (Chang et al 2008).

Nutritional problems are also common in haematological patients, particularly post-haematopoietic stem cell transplantation (HSCT). This can partly be attributed to the adverse effects of various drug therapies such as immunosuppressive agents and antibiotics that may be necessary for post-transplant management. Finally, the complication of graft-versus-host disease results in abdominal pain, nausea, severe diarrhoea, malabsorption, and substantial nitrogen losses. Patients who do not receive nutritional support or specialised nutritional support typically eat poorly for a prolonged period and are at high risk of poor nutritional status (Brown, 2001).

At Lifehouse, the decision to house the integrative medicine centre on the same site as conventional treatment facilities, surgical theatres and specialist consultation rooms was all part of integrating and streamlining our patients' care experience, as well as promoting dialogue between practitioners and clinicians across the spectrum of care. The overall feedback from clinical staff, patients and carers consulted in the process of designing the Lifehouse model of care was that more guidance was needed from clinicians and conventional care teams to help patients make decisions about appropriate modalities for their particular circumstances. Our approach with the LivingRoom is designed to empower patients and give them confidence in their treatment decisions in a safe and medically appropriate way.

At Lifehouse we're in a unique and fortunate position, being able to offer complementary therapies onsite in a purpose-built integrative medicine centre. That said, many of the LivingRoom's therapies are also available to non-Lifehouse cancer patients (dependent upon referrals or physician consultation as appropriate), as well as carers and the general public. Patients who may benefit from complementary therapies but are unable make it to Lifehouse should be encouraged to discuss options with their oncologist, GP or healthcare team and seek out a qualified practitioner. The practitioner should be appropriately certified, registered or accredited, have experience working with oncology patients and have an understanding of conventional cancer treatments.

Chris O'Brien Lifehouse

For more info on the integrative therapies available through the LivingRoom you can visit the website: http://www.mylifehouse.org.au/What_is_the_Livingroom.aspx

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Transfusion support in the critically ill

Transfusion Outcomes Research Collaborative
Seminar: Friday, 19th September 2014
AMREP Lecture Theatre, Alfred Hospital

TOPICS WILL INCLUDE:

- What is ECMO and how does it work?
- Platelet and granulocyte transfusions: should we use them?
- Case studies in sickle cell disease
- Ethical issues in transfusion support

Venue:	AMREP Lecture Theatre, Alfred Hospital
Date:	Friday, 19th September, 2014
Time:	9:00am - 5:00pm (Registration opens at 8.15am)
Cost:	$195.00 per person (including GST)
Website:	www.torc.org.au
Enquiries:	Tania Richter on 1800 811 326 or torc.sphpm@monash.edu
Registration:	Please go to: http://ecommerce.med.monash.edu.au/product.asp?pID=486&cID=8&c=2348 (NB. VISA or Mastercard ONLY)

Once payment transaction is completed on-line, you will automatically receive a tax invoice/receipt.

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research collaborative

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Transfusion support in the critically ill

AMREP Lecture Theatre, The Alfred Hospital, Ground Floor, 55 Commercial Rd, Prahran
Friday 19th September 2014

OPENING 9:00 - 9:15am	***Chair: Merrole Cole-Sinclair***
	Merrole Cole-Sinclair, Chair, Transfusion Outcomes Research Collaborative, welcome and introductions **John McNeil, Monash University** – welcome on behalf of Monash University **David Irving** – welcome on behalf of the Australian Red Cross Blood Service
FIRST SESSION 9:15 - 11:00am	***Chair: David Irving***
09:15 – 09:45am	**Heather Cleland, Alfred Health** - Transfusion support requirements for major burns
09:45 – 10:15am	**Jake Shortt, Monash Health & Peter MacCallum Cancer Centre** - New insights into the pathophysiology and management of thrombotic thrombocytopenic purpura (TTP): implications for therapy including plasma exchange
10:15 – 11:00am	**Anthea Greenway, Royal Children's Hospital** - Red cell exchange therapy for sickle cell disease
11:00 - 11:30am	***MORNING TEA***
SECOND SESSION 11:30 - 1pm	***Chair: John McNeil***
11:30 – 12:00pm	**Simon Harrison, Peter MacCallum Cancer Centre** - How do granulocyte transfusions work and when should we use them?
12:00 – 12:30pm	**Gemma Crighton, RCH, Australian Red Cross Blood Service & Monash University** - When and why should we transfuse platelets prophylactically?
12:30 – 1:00pm	**Neurologist (TBC)** - IVIG in acute neurologic syndromes
1:00 – 1:45pm	***LUNCH***
THIRD SESSION 1:45-3:15pm	***Chair: Jamie Cooper***
1:45 – 2:15pm	**Deirdre Murphy, Alfred Health** - What is ECMO and how does it work?
2:15 – 2:45pm	**Geoff Isbister, University of Newcastle** - Snakebite coagulopathy and bleeding
2:45 – 3:15pm	**David Roxby, SA Pathology** - The role of point-of-care testing in guiding transfusion support for critical bleeding
3:15 - 3:45pm	***AFTERNOON TEA***
FINAL SESSION 3:45 - 5:00pm	
3:45 – 4:15pm	**Zoe McQuilten, Monash University & St Vincent's Hospital** - Is the age of blood transfused important for patient outcomes?
4:15 – 5:00pm	**Panel discussion: Ethical issues in transfusion support in the critically ill** **Interactive question and answer session with panel** ***Chair: Bebe Loff*** Panel: A multidisciplinary panel of local and national experts

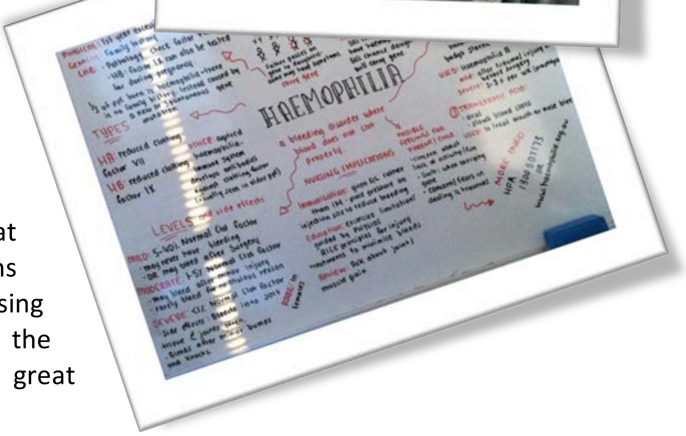
Haematology and Oncology Nursing in the Eyes of a New Graduate

Trudy Butler, *Transitioning Registered Nurse***,** *Sydney Children's Hospital*

When I was first asked to write a piece for this magazine, I wondered what I could possibly share with others that would interest them enough to read… you see, I haven't been nursing long. I am a new graduate and I had my first experiences as an enrolled nurse in an orthopaedic ward. I was offered an experience as a student to work within a paediatric haematology/oncology team, I knew then, that was the nursing I was supposed to be doing. I was luckily enough selected to do my first rotation this year as a new graduate in a haematology/oncology clinic. I have already learnt so much about blood disorders, autoimmune diseases and cancers. I am constantly amazed by research, new drugs and am determined to learn more and more about the body's cells and how they respond to treatment.

I found my most profound discovery about haematology/oncology nursing was that it is much more than understanding the body, understanding treatments or developing clinical skills. It is about having empathy, developing trust and knowing what to say, when to say it or even just knowing when to say nothing at all. Haematology/oncology nursing has taught me to more appreciate the most important things in life (family, friends and good health). It may sound almost selfish that I appreciate working in this field because it has and will continue to help me develop life, communication skills and coping mechanisms. I do however hope those developed skills are evident in my practice. I hope I make a difference to my patient's day and their family's time during treatment.

I am passionate about holistic care and I like to think my practice represents this. I am thoughtful when encouraging the haematology patient to learn skills to become more independent during their treatment or allowing the oncology patient to make simple decisions regarding the procedures they need to have. These disease processes and treatments when seen daily by nurses can seemingly become quite 'normal'. I believe, recalling and being empathetic about the interruptions to family life that spending time in hospital can have is particularly important. Being reminded that painful treatments, nasty side effects to medications and restrictions on daily norms have effect on patients and their families. Recognising and responding appropriately to these effects and offering the appropriate support is what I believe makes the difference in a great haematology/oncology nurse.



My next rotation I will have the opportunity to work on the haematology/oncology ward. I look forward to further developing these skills and hope to become just as accomplished as the haematology/oncology nurses I have already had the pleasure of working beside. I anticipate looking back at this article with the same passion and once again remind myself of the importance in maintaining the compassion, respect, knowledge, professionalism, and empathetic skills needed to be a haematology/oncology nurse. I also hope this article has reminded other nurses of the most important skills they possess in making a patient and families journey through treatment easier. And possibly encourage those just starting out to join the haematology/oncology team.

HAEMATOLOGY TEA ROOM QUIZ

Nikki Waters, *RN Sydney Children's Hospital, Randwick*

(Answers available on page 31.... NO cheating now!)

Questions

1. **During an acute sickle cell crisis, treatment includes which of the following**
    a. Oxygen therapy
    b. Intravenous fluids
    c. Analgesia-including narcotics
    d. All of the above

2. **Which of the following are the "B Symptoms" associated with Hodgkin's or non-Hodgkin's Lymphoma?**
    a. Fever, night sweats, weight loss
    b. Fever, lethargy, headaches
    c. Weight loss, enlarged lymph nodes, cold intolerance
    d. Night sweats, joint aches, fever

3. **Aplastic anaemia is a condition in which the bone marrow fails to produce?**
    a. Red blood cells
    b. White blood cells
    c. Platelets
    d. All of the above

4. **A patient presents with bruising, lethargy, pallor, and the following results on an FBC: WBC 20,000; Platelets 30; Haemoglobin 62. Which of the following would be the most likely cause?**
    a. sickle cell anaemia
    b. leukaemia
    c. haemophilia
    d. ITP

5. **Name the four main types of leukaemia.**

6. **What is the most common type of haematological malignancy in childhood?**

7. **Which type of malignancy contains abnormal cells called 'Reed-Sternberg cells'?**

8. **The term "recombinant" is often used when discussing haemophilia clotting factors. What does the term "recombinant" mean?**

9. **What type of medications are the following; Xyntha, Kogenate FS, Advate?**

Medicine, Nursing and Health Sciences

The Myeloma & Related Diseases Registry Interest Group Meeting at HAA 2014

Invitation

The Myeloma and Related Diseases Registry (MRDR) research team invite you to the annual MRDR Interest Group Meeting 2014 for an update of registry progress

Details

Monday, 20 October 2014

Time: 7:15 AM—8:15 AM
A light breakfast will be provided from 7am onwards

Venue: Room 9, Perth Convention and Exhibition Centre, WA

RSVP: (for catering purposes) no later than Monday 29 September 2014 to Gabrielle Abelskamp on +613 9903 0355 or *torc.sphpm@monash.edu*

MONASH University

AlfredHealth

Myeloma & related diseases registry

A C B D
Australian Centre for Blood Diseases

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Medicine, Nursing and Health Sciences

News from the Myeloma and Related Diseases Registry

Upcoming events

The MRDR research team will host an interest group meeting at HAA on Monday 20 October from 7:00 AM – 8:15 AM in Room 9 at the Perth Convention and Exhibition Centre. The session will be a breakfast meeting and will focus on initial results from the registry. RSVP by Monday 29 September (for catering purposes) at: torc.sphpm@monash.edu or Gabrielle Abelskamp on 03 9903 0355.

Meet the MRDR's

Coordinating Principal Investigator, Professor Andrew Spencer.

Why did you become interested in the field of myeloma?

It's a common haematological cancer and hospital departments see a lot of myeloma. It is a disease where you follow your patients up for a long time and therefore develop fairly strong relationship with them. And it was evident that the therapy for these patients was very inadequate, at least when I first started practicing as a haematologist. And so I actually initiated the first clinical trial I ever designed in myeloma back in the late 1990s and so from that point onwards, my interest in the disease has just escalated in many directions.

What inspired you to establish the MRDR?

A variety of things. I remain alarmed at the variation in care that I see happening for myeloma patients and sometimes I see that patients are really not managed in a way which is consistent with what evidence would support. So having the registry is a way for us to objectively look at how patients are treated and that can enable us to educate people in a broader sense. Secondly, the disease is very variable in its presentation and the underlying genetic causes of it and so we need to study large numbers of patients to understand it better. And having a registry is clearly a way of collecting data on large numbers of patients and is a tool which can be used for specific studies asking questions. So it provides a mechanism for further research.

MRDR Sites in Australia and New Zealand

Recruitment Update

Registered cases continue to climb, with over 450 cases listed as of July 2014. There are currently 14 sites with ethics approval.

Do you remain concerned at the variation in care?

Yes, I still see patients who I believe have not been treated in a way consistent within contemporary practice. So even within 12 months, I've seen people that fit that category.

What does a typical day involve for you?

I wear a number of hats. My day job is running the bone marrow transplant program and the malignant haematology program at The Alfred Hospital (Melbourne) so that involves administrative work and clinical work but I also have a laboratory research group and so I spend time most days interacting with the people in the laboratory research group. And I also run the clinical research unit so I spend a lot of time involved in the clinical trials side, either seeing the patients or interacting with the trial coordinators and addressing issues to do with the trials. So most days have a range of activities from those three main areas.

How will the MRDR benefit patients and health professionals now and into the future?

Well I think if it leads to the delivery of better care and enables research focussing on new types of treatment it will benefit patients in the future. Clearly it's like any intervention that we undertake. It might not benefit people right now but it's building a structure which may have benefit in the longer term.

What are some of the biggest challenges ahead in myeloma research?

Probably the single biggest challenge is the increasing awareness that genetically the disease is incredibly complicated. And far more complicated than most other types of blood cancers and therefore that will present very big challenges in terms of developing more effective therapies or specific therapies. Whereas in some other blood cancers you can use agents that will essentially just target one specific abnormalities and they're effective. That's very unlikely to be the case in myeloma.

How do you like to spend your time when not working to cure myeloma?

Hanging out with my family, I like cooking and going to the cinema and dining out.

How the MRDR can help you

The MRDR collects detailed assessment and treatment information in one central location that can be used by multiple team members. At RPAH, the registry is used by haematologists, the bone marrow transplant coordinator and clinical nurse consultant for their own specific needs. This avoids duplication of work and saves the team valuable time.

How can you help?

If your hospital is not participating in the MRDR and you would like information about how to join the registry, contact the research team on: 1800 811 326 or email torc.sphpm@monash.edu

MONASH University | AlfredHealth

Formation of the Australian Haemoglobinopathy Nurses Network (AHNN)

Grainne Dunne, *CNC Haematology/Apheresis SCH, NSW*

Haemoglobinopathies are a group of genetic blood disorders whereby the haemoglobin molecule is unable to form correctly and over time the body becomes chronically anaemic. Examples of haemoglobinopathies are Thalassaemia, Sickle Cell Disease, Sickle-Thalassaemia and Black Fan Diamond Disease. There are different severities and sub-types of these individual disorders, which together with other elements can make haemoglobinopathies complex disorders to manage well. Treatment of the most severe forms require chronic, regular (mostly 4 weekly), red blood cell transfusions. Without these transfusions, many patients would not survive to adulthood. However while administering such lifesaving chronic blood transfusions; it also adds another layer of complexity of the management of haemoglobinopathies.

Managing chronic disorders can be very challenging for any healthcare professional. Of course, when the disorder is rare it only makes the challenges greater again and even more isolating for both the health carer and for the patient. In Australia, haemoglobinopathies are primarily managed in a small number of haematology centers around the country; centers who are committed to specializing in this area of care. As such, this requires specialized haematologists and specialized nurses experienced in the needs and treatment of a somewhat small and yet challenging population of haematology patients. Medical professionals often need to seek advice and medical support from known peers, both nationally and internationally. In the area of Australian haemoglobinopathy care, this appears to be more commonly practiced amongst medical clinicians than it does amongst the nursing specialists - up until now.

On May 18th 2014, a small group comprising of 6 nurses and 4 members from Thalassemia Australia and The Thalassaemia Society of NSW met in Melbourne to formulate the first ever "Australian Haemoglobinopathy Nurses Network" (AHNN). The fundamental purpose of this group is to provide a forum through which Australian nurses in this specialized area of care can come together to give and receive support, advice and education. The main aim of the group is to improve haemoglobinopathy nursing care and services within Australia.

The Australian Haemoglobinopathy Nurses Network was established as a sub-committee of the Thalassaemia Australia/Thalassaemia Society of NSW and is supported by Thalassaemia Australia/Thalassaemia Society of NSW. It is hoped that over time, the group will grow successfully in number, strength and functionality.

At a starting point, the group will meet face to face once every two years. It will maintain ongoing telecommunications via group email, teleconference and as required internet web usage. In general, the group will act as a repository for knowledge learning amongst Australian nursing peers.

Membership is through application to the group chair and is free of charge. Australian nurses working in a role, which has a specialty component of haemoglobinopathy patient care, are encouraged to become members and participate in this specialist group.

For more details and membership information, please contact the current Chair of this new group:

Adrienne Woods: adrienne.woods@health.nsw.gov.au or Ph: 02 9845 0000 and page 6273.

The Impact of disease and treatment regimens on the psychosocial status and lifestyle of haematological cancer patients and their families

Daniela Klarica, Stem Cell Transplant Coordinator / Myeloma Nurse Practitioner Candidate, Malignant Haematology & Stem Cell Transplant Service, The Alfred Hospital Melbourne.

This year I commenced as a Nurse Practitioner Candidate at The Alfred Hospital, Melbourne. I also commenced my master's studies – a requirement to become endorsed as a nurse practitioner. It was many years since I last studied and I felt nervous about coordinating study, work and personal life. I was fortunate enough to ease my way back into study by undertaking two professional development units during the summer break. One of the units I chose was a cancer based unit and the assessment focused on the psychosocial status of haematological cancer patients and their families, an area I am passionate about. *The following is a short excerpt from my assessment during this unit.*

Psychosocial support is 'the culturally sensitive provision of psychological, social and spiritual care' (National Breast Cancer Centre & National Cancer Control Initiative 2003) and involves all members of a patient's multi-disciplinary team, family, friends and carers (Botti et al. 2006). As stated in the clinical practice guidelines for the psychosocial care of adults with cancer adopted by the National Breast Cancer Centre and the National Cancer Control Initiative (2003), 'psychosocial care begins from the time of initial diagnosis, through treatment, recovery and survivorship, or through the move from curative to non-curative aims of treatment, initiation of palliative care, death and bereavement.'

Patients diagnosed with haematological malignancies often require urgent specialist treatment administered over an extended treatment trajectory including high dose chemotherapy, total body irradiation and stem cell transplantation. Treatments can result in a range of complex and debilitating physical and psychological side effects and can have a devastating impact on the lives of patients and their families. Adapting to a new diagnosis can be a traumatic time for patients and their families, and the information they receive is often difficult to understand due to its complexity and unfamiliarity (Savage 2013). Nurses, because of their frequent contact with patients are in a unique position to monitor a patient's psychosocial coping and distress (Legg 2012).

Following diagnosis haematological patients are drawn into unfamiliar environments. Treatment regimens are long, aggressive, have numerous side effects and may require long stays in hospital. Patients need to be well prepared, given the appropriate education and be helped to maintain a sense of control. The impact caused to each patient and their family will be a unique experience. Factors such as age, diagnosis, prognosis will have an impact however, there will be many emotional factors experienced including grief, fear, anger, powerlessness, loss of control, anxiety and depression (Downing 2000, p. 250).

There is also increasing recognition of the impact that a cancer diagnosis and treatment has on families. Many family members assume a caregiver role and often feel ill prepared for this role and may experience issues such as lack of support, as well as relationship, work and financial concerns. Caregivers may also experience physical symptoms such as sleep deprivation and fatigue that may trigger emotional distress (Cooke, Gemmill & Grant 2009). In a study looking at 'Unmet supportive care needs, psychological well-being and quality of life in patients living with multiple myeloma and their partners,' Molassiotis et al. (2011) found there was a high incidence of anxiety and depression amongst these two groups. Interestingly, the partners of patients with myeloma reported a higher level of psychological distress than the patients themselves. Partners of patients assume the caregiving role with little preparation and often have limited opportunity to discuss their needs with health care professionals.

To provide effective psychosocial care nurses need the appropriate assessment and communication skills (Legg 2012). Effective communication is central to the identification of individuals' specific needs and the provision of appropriate information and psychosocial support. Nurses are in a unique position to recognise and understand the emotions that haematology patients experience when undergoing treatment for haematological malignancies. They have an important role to play in the delivery of their care by supporting patients and their families, being sensitive to their needs in an environment where patients feel safe and comfortable to communicate and relate (Legg 2010).

Despite the role nurses play in providing psychosocial care to their patients, hurdles will be experienced. Providing psychosocial care can place specific burdens on health care professionals. The effectiveness of care provided is dependent on the training, skills, attitudes and beliefs of staff (Botti et al. 2006). A study conducted by Botti aiming to identify the key issues in providing psychosocial care to haematological cancer patients as perceived using two focus groups of registered nurses was explored. Botti found a number of barriers existed including high workload and lack of time to engage in conversation, ineffective communication between doctors and nurses in relation to the timing of communication to patients and the professional and personal impact on nurses (Botti et al 2006). Furthermore, Botti stated that nurses in both groups felt they were vulnerable to becoming emotionally drained by being drawn into the patients emotional world. For this reason most nurses felt that setting their own personal boundaries helped.

Finally, psychosocial factors affect haematology patients in varying capacities. From diagnosis, through treatment to remission, survivorship and possibly end of life care, regardless of the end result, the journey travelled will have an immense impact on an individual and their family. Nurses play an important role in the provision of psychosocial care by providing effective communication, using empathy and support and ensuring that information conveyed is accurate and understood. However, some barriers will be encountered by nurses caring for this patient group commonly experienced when patients ask nurses a difficult question or when high workload is experienced and nurses have inadequate time to engage with their patient. For these reasons it is important that nurses are given adequate support to help them address these issues with their patients and their families.

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IMPROVING OUTCOMES FOR SURVIVAL AND OPTIMAL RECOVERY FOR CANCER PATIENTS

Specialist education for nurses who work in all areas of cancer and haematology nursing

Cancer is the single largest cause of premature death and represents nearly one-fifth of the total burden of disease in Australia. This is set to increase substantially over the next decade.

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Cancer is the single largest cause of premature death and represents nearly one-fifth of the total burden of disease in Australia. This is set to increase substantially over the next decade. In this context there is increasing recognition that specialist cancer services improve outcomes and benefit both survival and optimal recovery for cancer patients.

Nurses are essential to providing support to patients and their families. With specialised skills and knowledge you will contribute to important decisions about future trends in treatment, patient care and disease prevention.

COURSE OVERVIEW

The Cancer and Haematology Nursing program is offered at graduate certificate, graduate diploma and master's degree levels. The graduate certificate and graduate diploma are embedded within the master's degree. There is one intake each year in March.

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Credit points	60
Full-time enrolment	1.5 years (or part-time equivalent)

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Credit points	48
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Credit points	24
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Each unit of study has four compulsory on-campus study days per semester offered in block mode. The study days are supplemented by flexible and independent online study, supported by the University of Sydney's eLearning platform.

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If you have a particular interest in research, you have the option to take a research stream within any of Sydney Nursing School's specialty degrees, This stream will develop your research skills and knowledge. It is also a pathway into the PhD program at Sydney Nursing School.

Shannon Philp, Course Coordinator Cancer and Haematology Nursing

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Please apply online. You can also upload certified copies of your documentation and any other forms required as part of the online application process. Both domestic and international students submit your applications at http://sydney.edu.au/courses/programs/master-of-cancer-and-haematology-nursing

The application closing date for the March intake is 31 January.

WANT MORE INFORMATION ABOUT THIS COURSE?
You can find more nformation about the Cancer and Haematology Nursing program, including fees, on our website: sydney.edu.au/nursing/course_information/specialty_courses/specialty_courses_index.shtml

WHAT WILL YOU STUDY?

YEAR 1 PART TIME STUDY PATTERN		YEAR 2 PART TIME STUDY PATTERN	
SEMESTER 1	SEMESTER 2	SEMESTER 1	SEMESTER 2
ASSESSMENT AND CLINICAL JUDGEMENT	CANCER AND HAEMATOLOGY NURSING PRACTICE	RESEARCH IN NURSING AND HEALTH CARE	*STUDENTS MUST CHOOSE 2 UNITS FROM THE FOLOWING 3 OPTIONS:* CREATING A CULTURE OF SAFETY AND QUALITY
THE BIOLOGY OF CANCER AND HAEMATOLOGY	NAVIGATING THE CANCER EXPERIENCE	EXPANDING CANCER AND HAEMATOLOGY PRACTICE	CONTEMPORARY NURSING LEADERSHIP
			SIMULATION-BASED LEARNING IN HEALTH

YEAR 3 PART TIME STUDY PATTERN

SEMESTER 1	CAPSTONE (WORK-BASED PROJECT) OR CAPTSONE (THESIS)

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You'll be learning from leading academic and clinical experts in cancer and haematology nursing. The course coordinator is Shannon Philp. Shannon has nearly 20 years experience in cancer nursing and is an endorsed Nurse Practitioner. She works conjointly in a senior clinical role as a Nurse Practitioner at Chris O'Brien Lifehouse.

You will also have access to the expertise of the Cancer Nursing Research Unit. Led by Professor Kate White the Cancer Nursing Research Unit is an innovative collaboration between Sydney Nursing School, the Cancer Institute of New South Wales and the Sydney Cancer Centre, Royal Prince Alfred Hospital.

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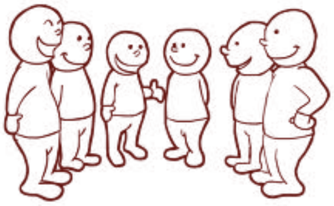


The Talking Corner

Toni Lindsay
Clinical Psychologist
Psycho-Oncology Team
Chris O'Brien Lifehouse, Sydney.

Well, it's that time again! Let's revisit the Psychologists corner! We have had some great questions about AYA (adolescent and young adult) patients. These are the patients that seem to cause the most distress and anxiety for health care professionals, and are often the patients that we carry with us and think about after we have left for the day.

Q. I have a young patient who gets quite distressed and upset on the ward, and becomes quite withdrawn, particularly when his parents are around. He has had lots of treatment and has spent heaps of time in hospital over the last year. Should we be worried about depression?

A. Young people often find it more difficult to manage hospital admissions than our older patients, particularly if they are in a shared space, or exposed to confronting things (for instance being in a ward with people with end stage disease can be very frightening and overwhelming for a young person). In my experience, young people develop very good skills for managing their admissions, and often this includes hibernating away behind the curtains and trying to sleep through it all. Younger patients sometimes find procedures much harder to manage than adults, and so when they are on the ward and being constantly exposed to procedures, they will have an increase in anxiety and distress, and manage this by becoming withdrawn and not wanting to engage in conversations about the treatment or the admission (sometimes defaulting to their parents). In an AYA patient, being withdrawn whilst in hospital isn't enough to meet the criteria for depression. However, if this is also happening at home, they have stopped talking with friends (Facebook, text, email, snapchat etc), they are more irritable than normal (outside of what you would expect on treatment), and they are speaking about themes of hopelessness or helplessness, it is worth considering a review by a psychologist/psychiatrist to evaluate. Of course if a patient is talking about self-harm, wanting to stop treatment or talking about there "being no point", they always require review. Sometimes, if you talk with our younger patients about what they are into, and usually if you catch them when their parents aren't around, they are much easier to engage.

Q. My young patient who is 17, has metastatic disease and is deteriorating, but I feel like the medical team and his parents aren't letting him know what's really going on. He keeps talking about doing things in the future, like going to schoolies (which is a long time away) and he is quite unrealistic. Should I talk with him about it?

A. In my experience, there are very few patients who don't know what's going on, even if we don't tell them. Part of the reason for this is that their bodies let them know that things aren't ok, as well as all of the people around them usually start behaving differently. Your patient is old enough to engage in conversations about their future and disease progression, and should have the opportunity to make decisions about what they want to happen. That said, often medical teams and parents feel like they are being helpful by protecting young people from their situation, and worry that by telling them they will ruin the time that they might have left. I think simply going and telling the young person about their situation will probably be pretty unproductive (for both you and them), but perhaps if they start talking about being worried or concerned about what might happen to them, it might be ok to ask some gentle questions about what they are worried about and what might help. Unless you have a very good relationship, patients will not respond well to answering questions like this as it is very personal and confronting. Often, young people will not talk with their teams or the people around them, but will have spoken with the psychologist, social worker, friends, a teacher, or another person close to them, and won't need to talk about it anymore.

The other factor in this situation is the sense that things feel unrealistic. All of us have some unrealistic thoughts and hopes, and in this situation they do not cause any harm, they simply allow the young person to put their energy into thinking about something nice, rather than where they actually are. Unless they are going to do something dangerous or harmful, it's ok for them to dream about where they want to get to, even if they aren't going to get there.

Keep the questions coming….Until next time,

The Psychs! (Toni Lindsay and Nicole Ferrar)

Cancer Council NSW

National Telephone Support Groups

for people living with MYELOMA and their CARERS

"I'm so pleased to hear others in the group talk about what I've been feeling." *Myeloma Group Member*

When Joe was diagnosed with Multiple Myeloma in 2012 he was living in an **isolated** region of Australia and was the only person he knew living with the disease. He was keen to speak to others who would **understand** what he was going through. He wondered how others were **coping** with their diagnosis and how they were living day to day **managing symptoms, treatment and emotions**. He joined the Telephone Support Group and found a place where feelings and practical experiences of living with Myeloma could be **shared** in an environment of mutual **understanding and support**.

Myeloma Telephone Support Group

2nd and 4th Wednesday of each month

1:30 - 2:30pm

Carer Telephone Support Group

2nd and 4th Monday of each month

1:30 - 2:30pm

For more information, please contact the Telephone Support Group Team:

Tel: 1300 755 632
Email: tsg@nswcc.org.au

The benefits of Telephone Support Groups

- **Participation is free** – we call *patients and carers for group* at no cost to them
- Access **Australia wide** support, by landline or mobile
- **Connect** with others living with the **same cancer or similar circumstance**
- **No need to travel** to attend group. Patients and carers can connect with others from the comfort of their home, or any quiet, private space
- Groups are **professionally facilitated** and **confidential**

www.cancercouncil.com.au/supportalk

World Federation of Haemophilia (WFH) Congress Report, May 11th – 15th 2014 Melbourne, Australia

Dale Rodney (Mrs), *Haemophilia Clinical Nurse Consultant. Haemophilia Treatment Centre, Calvary Mater Newcastle, NSW.*

It was recently my great privilege to attend the biennial World Federation of Haemophilia (WFH) Congress – the first to be hosted by Australia. This also happened to be my first official Haemophilia conference since taking up my current post in January 2013 at the Calvary Mater Newcastle.

Since the last WFH congress in the city of Paris in 2012, there has been an almost palpable level of excitement and anticipation leading up to the 11th of May this year when it was Melbourne's and Australia's turn to shine. The Melbourne Exhibition and Convention centre (MCEC) located on the banks of the Yarra River was a stunning venue for this gathering of those whose lives are either affected by a bleeding disorder in some way, as well as the many important professional groups who represent the comprehensive care team for persons with bleeding disorders and their families.

This WFH congress was attended by 4,300 delegates from more than 120 countries with our international visitors clearly impressed with what they were experiencing. The opening ceremony featured a traditional aboriginal welcome and dance performances which were warmly received. Following this was a rather impressive cocktail reception which provided an opportunity for all to mingle, relax and meet new people. The cultural evening on the Tuesday night was well attended and gave delegates a "taste of Australia" with not only great food, wine and beer from around Australia, but some roaming "Aussie" animals (the dressed up human kind!) to entertain the crowd and provide "one of a kind" photo opportunities.

As expected, the congress featured a full program beginning on the Sunday before the start of the congress with the Nurses Workshop – "Nurses: Triage to Triumph". This workshop included topics which discussed the benefits of Telemedicine – significant in the ever-increasing shift to outpatient care, and instrumental in improving care for patients and families living with a bleeding disorder in regional and remote areas. The successful use of telephone clinic protocols in Canada, the current era of electronic record keeping (E-Logs) via social media, smart phone/computer applications to enhance patient care and outcomes, and a presentation on sustaining Haemophilia nursing positions within an activity based funding environment also covered very relevant and interesting points and gave rise to plenty of interactive discussion.

There was of course a large variety of concurrent sessions daily to choose from with the usual lunchtime and evening Symposiums. The quality and breadth of the presentations was impressive, and attempting to fit in as much as possible from as many sessions as possible was a daily challenge. The sheer size and layout of the MCEC ensured that between sessions, delegates either willingly or unwillingly, got their daily exercise!

The poster presentations for WFH congress numbered 237 with an astounding variety of subjects and studies covered, and the trade exhibition area was also consistently busy providing the opportunity to speak with those in the field and hear about the latest innovations, review and collect resources, and for many just relax with a coffee in between sessions.

During congress, WFH provided a treatment room where those needing assessment or access to clotting factor concentrates, were managed by nurses, physicians and physiotherapists from the Australian Haemophilia Treatment Centres – operating on a roster and volunteer basis. WFH volunteers did a fantastic job manning the treatment room front desk and triaging patients requiring treatment or assistance. My brief experience in the

treatment room was most fulfilling and a great opportunity to meet delegates with bleeding disorders from all over the world and learn a bit about their experiences compared to us here in Australia. Special mention and thanks to Andrew Atkins for all his hard work and dedication in setting up the treatment room.

Session Focus: "**Challenges and Solutions in Haemophilia B treatment adherence – Focus on adolescents"** (Regina Butler).

An important question was raised. **"Non-adherence – whose fault is it?"**

It has been identified that health care providers can unwittingly contribute to treatment non-adherence by their patients by the following means. Not acknowledging the patient's lifestyle and how treatment impacts on this; a sub-optimal relationship between the patient and health care provider; the complexity and duration of the treatment protocols or regimens the patient is encouraged to adhere to, and symptom relief (in the setting of acute bleeding) vs prevention (prophylaxis).

Challenges involving the level of skill in relation to venous access, cost, and overprotective parents and Haemophilia Treatment Centres, can also act to delay the adolescents desire or motivation to take responsibility for managing their haemophilia.

Adolescents are generally powerless in chronic health situations. They are often inconsistent in their ability to think formally, and crave peer acceptance - not wishing to be different. Both anxiety and depression are also well recognised in the general adolescent population whether they are living with haemophilia or not and this has been identified as a potential barrier to adhering to routine treatment.

Also acknowledged by other speakers on the same subject, addressing the problem of non-adherence should be targeted via thorough assessment, identifying perceived or actual barriers to treatment adherence, providing education and encouraging constructive dialogue between patient and healthcare provider, and adopting and applying multi-dimensional strategies to encourage adherence including behavioural change. By developing an individualised plan of care for the patient with a factor IX deficiency to work around issues and advocating for and empowering the adolescent, significant improvements in treatment adherence are practically possible.

Finally, this was a most successful congress and I believe all involved certainly did Melbourne and Australia proud! I am sure that we will all be talking about the experience for a long time to come. The next WFH congress in 2016 is in Orlando, Florida.

An Eye-opening Conference: "World Federation of Hemophilia Congress" May 2014

Renee Gilmore
Clinical Nurse Educator, C2West Inpatient Haematology/Oncology, Sydney Children's Hospital, Randwick

This May I was fortunate enough to receive a grant from HSANZ NG and Bayer Health to attend the World Federation of Haemophilia (WHF) 2014 World Congress in Melbourne Australia. I would like to thank HSANZ NG and Bayer Health for providing the opportunity for myself and other nurses to attend the congress, as it was a truly enriching experience.

I work in the inpatient paediatric Haematology/ Oncology ward at Sydney Children's Hospital. We occasionally have patients admitted to us with bleeding disorders. Due to the rareness of the disease we usually only see these patients when they are diagnosed, having a surgical procedure, have infected port-a-caths or if they experience a severe bleeding episode. Our patients are managed primarily as outpatients and therefore, nurses on the inpatient wards have limited exposure to bleeding disorders. During my time at the congress I learnt far more than I expected about various bleeding disorders, management of the disease, and future therapies. This has provided me with a solid foundation of the principles of Haemophilia and other bleeding disorders of which I can disseminate to my colleagues.

During the conference, many different speakers presented the idea that the role of the Haemophilia nurse is not well defined. At first I was confused about this idea; what do they mean we don't know what our role is? But the more I thought about it and the more times this topic was explored it became clearer. All of us can define our role in caring for people with bleeding disorders, however there are large portions of the job where we provide safe and effective care to our patients which is hard to explain, and is not explicitly found in job descriptions. Tasks such as coordinating care, managing clinics and factor supplies is a large proportion of the role, along with patient and family education regarding factor therapies and lifestyle choices. In the role, we perform procedures for patients; provide counselling and endless hours of patient support. But what else do you do? Would you say your hospital executive could accurately describe the work you do within your role?

This is a topic that I feel should be explored further and perhaps better defined, especially in light of the upcoming activity based funding (ABF). Every procedure or intervention will need to be billed, and many Clinical Nurse Specialist (CNS), Clinical Nurse Consultant (CNC) and Nurse Practitioner (NP) roles may struggle to generate accurate funding for the valuable work they do. While NPs have provider numbers and are able to generate funding for specific tasks, they are very limited in what is billable under ABF. That leads me to the question of, 'what will happen to the Haemophilia Nurse (CNS,CNC,NP) as the systems move to ABF?'.

Another major theme that left an impression on me was the disparity between the treatment options and disease trajectories between the developing and the developed worlds. As I have had limited exposure to Haemophilia during my career, I was surprised to learn about the wonderful advances in Haemophilia treatments. What I had never considered was the major gap between the developing world and the developed world. Many countries in Africa and in the Middle East presented their journeys in starting up Haemophilia Treatment Centres and providing basic education and treatments when they are able to. In some countries, getting patients diagnosed is still a challenge as the access to medical centres and appropriately trained staff is very difficult. Many developing countries are not able to provide regular factor supplies due to the cost and availability which impedes the ability to provide factor treatment. Many people with Haemophilia only get factor concentrates when they have a severe bleed, and it is often given days after the bleed occurred. This leads to more severe complications such as arthritis, joint disfigurement, loss of joint range of motion in those populations and sometimes death.

At WHF I was able to meet a few delegates (also patients) from developing countries who had obvious arthritic joint complications. It was heartbreaking to see, as these people have been physically impacted significantly more than the people with Haemophilia I had met from developed nations.

In the developed world, Haemophilia treatments are on the brink of major change. The concept of long acting factor concentrates has been developed and some are already being tested in clinical trials – one of which is ready for the adult patient market now. When these therapies become available it is predicted to increase length of time that the factor concentrate will remain in the body. This will mean less frequent prophylaxis injections, less time where a patient will have minimal factor levels in their body and hopefully less bleeding episodes. These new factors are expected to be costly, however it is hoped that they will lead to cost savings with their effect on reduced bleeding episodes, fewer health care interventions and disease complications.

One of the most powerful experiences I have taken away from the congress is hearing the hope for future treatments option, whether it be for those in the developing or developed world. I truly believe that no matter where you live in the world it is a very exciting time to be a Haemophilia Nurse.

Acute pain in severe haemophilia

Daniela Karanfilovska, *Registered Nurse, Haematology and BMT, The Alfred Hospital, VIC*

In May 2014, the World Federation of Hemophilia (WFH) World Congress was held in Melbourne. This is an international, biennial event which brings health care professionals and people with haemophilia (PWH) and their families together to discuss current issues and future directions in haemophilia management. From the nursing discipline, there were over 100 nurses represented from more than 20 countries. This year, I had the privilege of attending the Congress for the first time with thanks to HSANZ Nurses Group and Biogen Idec.

I work on an acute haematology unit in a busy metropolitan hospital, and our main experience with PWH is when they are admitted with severe bleeds. These are usually joint bleeds, where the prominent clinical issues tend to be uncontrolled pain and loss of function. My motivation in attending the Congress was to investigate how we can improve the multidisciplinary management of these patients on the ward. The way we manage these acute admissions has significant implications in how we influence the patient's attitude to their condition, and also their treatment-seeking behaviour.

There were a number of sessions based on the management of chronic pain, and musculoskeletal changes seen in PWH. These helped me to understand the experience of my patients in their daily lives, and that recurrent bleeds into the same joint will result in chronic synovitis, arthropathy, and deformity. Pain is often central to the lives of PWH, particularly for those who did not commence prophylaxis until later in life when it became available. Pain may be chronic, acute, or a mixture of both. Only recently has groundbreaking research started to try and characterise the pain experience of PWH; Witkop et al. (2012), Holstein et al. (2012), and Elander (2014) were among some of the most quoted and discussed studies at the Congress. Their focus, however, was on the chronic pain issues associated with haemophilia. What the literature shows us and what was also confirmed at the Congress, is that there is a lack of evidence-based guidelines for the management of pain in PWH, particularly in relation to the pain associated with acute bleeds.

So, until there is further research into this area, what did the various experts at the Congress suggest? Treatment with factor, primarily, is always the first, vital step. But while factor can stop the bleeding and some of the associated pain, it does not prevent the damage to the joint that follows. Varying combinations of rest, ice, compression and elevation (RICE) continue to be the cornerstone of treatment that both PWH and the health care teams rely on; several physiotherapists urged me to find funding for CryoCuff products on the ward. However, while the use of ice can help to alleviate pain, it possibly interferes with coagulation and haemostasis (Forsyth et al., 2013). Aspiration or surgery can also be of benefit to some PWH, though the risks and benefits of this need to be weighed up carefully.

The pharmacological management of acute pain, on the other hand, presents yet larger concerns. The Witkop et al. (2012) study showed that the use of analgesia was not even in the top five methods in the way that PWH managed their pain, which is reflective of a sceptical and complicated attitude of our haemophiliac patients towards pain medications. Paracetamol appears to be the first-line recommendation for the management of chronic and most likely acute pain in PWH if there is no risk of hepatotoxicity, but beyond this, the recommendations are not clear. The use of non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen and celecoxib, has been shown to be effective and safe (Witkop et al., 2011). The use of opioids, both short and long term, has not been studied in PWH and their use is sporadic. Several speakers discussed the benefits of employing the use of sedatives (diazepam), or intravenous analgesia such as morphine or tramadol. The ugly side to this is the stigma that comes attached to the use of any 'hard' analgesics. Much like other chronic pain sufferers, PWH may refuse or request certain drugs and this may inadvertently present as 'drug-seeking behaviour.' This only has negative consequences for the relationship between the patient and their treating team, even when there are genuine concerns regarding tolerance or misuse of analgesia. Such relationships can unfortunately be short-lived because of the ongoing rotation of medical registrars.

I have no doubt that over the next several years there will be significant advances in the management of acute pain in PWH. But what can we do, as nurses, for our patients on the ward in the meantime? First and foremost, we need to ensure that we taking a comprehensive pain assessment of our patient. Tools can be valuable, and there are several out there commonly used in PWH. We need to push for multidisciplinary involvement, particularly from those often forgotten such as rheumatology and the acute pain service. We need to be aware that at times, our advice to PWH may be contradictory to what they have always known– if we are saying that ice may not be the best option, or that many NSAIDs are considered to be safe. We need to ensure that our patients are having regular analgesia in order to help keep on top of the pain and not let it spiral out of control because the patient may be stubborn or doubtful about certain regimes. As nurses, we have a responsibility to keep trying, even if a patient has a history of non-compliance or being difficult, because this behaviour is not personally directed against us. Finally, and perhaps most importantly, we need to keep working towards a biopsychosocial approach because, as I heard numerous times at the Congress, "everybody bleeds differently".

1. Elander, J. (2014). A review of evidence about behavioural and psychological aspects of chronic joint pain among people with haemophilia. *Haemophilia, 20*(2), 168-175.
2. Forsyth, A.L., Zourikan, N., Rivard, G.E., & Valentino, L.A. (2013). An 'ice age' concept? The use of ice in the treatment of acute haemarthrosis in haemophilia. *Haemophilia, 19*(6), e393-396.
3. Holstein, K, Klamroth, R., Richard, M., Carbalho, M., Perez-Garrido, R. & Gringeri, A. (2012). Pain management in patients with haemophilia: a European survey. *Haemophilia, 18*, 743-752.
4. Witkop, M., Lambing, A., Divine, G., Kachalsky, E., Rushlow, D., & Dinnen, J. (2012). A national study of pain in the bleeding disorders community: a description of haemophilia pain. *Haemophilia, 18*, e115-119.
5. Witkop, M., Lambing, A., Kachalsky, E, Divine, G., Rushlow, D., & Dinnen, J. (2011). Assessment of acute and persistent pain management in patients with haemophilia. *Haemophilia, 17*, 612-619.

Clinical Audit and Questionnaire Design

Cathy Barnett, *PhD Senior Research Officer, Cancer Nursing Research Unit, Sydney Nursing School*

What is clinical audit?

Clinical audit is "a quality improvement process that seeks to improve patient care and outcomes through systematic review of care against explicit criteria and the implementation of change". (National Institute for Clinical Excellence) www.nice.org.uk. Its purpose is "first the improvement of care to individual patients, second the education and training of individual clinicians and third the effective use of resources" (page 3)(1). The audit cycle is shown in Figure 1.

Today, audits are multidisciplinary in nature, involving many or all members of the health-care team. The advantages of this are two-fold: (i) encouraging participation by different health care team members allows them to take ownership of the process of audit and reduces negative reactions which can sometimes surround the conduct of an audit, (ii) the multidisciplinary nature makes for an (arguably) more robust or successful, audit.

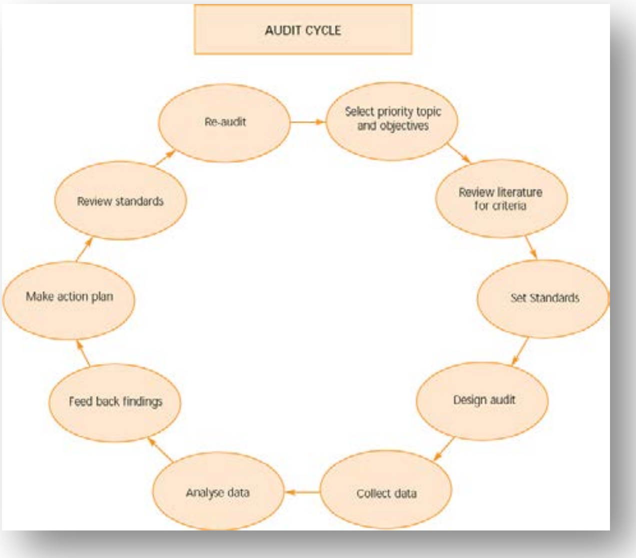


Figure 1.
http://www.selfcareconnect.co.uk/tools_sc4pc/img/tool9_audit_cycle.gif

Carrying out a clinical audit

The essential steps to undertaking a systematic approach to audit are as follows(1):

1. *Select topic* – factors to be considered here include (i) does the topic have an important impact on health? (ii) does it affect a large number of people? (iii) is convincing evidence available about appropriate care? (iv) are there good reasons for believing that current performance could be improved?
2. *Identify specific aims* – have clear, agreed aims.
3. *Agree target criteria and standards* – *Audit Criteria* are ‘systematically developed statements that can be used to assess the appropriateness of health care decisions, services and outcomes’ (page 7).

   They must be (i) evidence-based (ii) prioritised (iii) measurable (iv) appropriate to the setting. *Standards* are ‘the percentage of events that should comply with the criterion’ (page 7) and should be realistic and attainable.
4. *Devise method of data collection* – The most common audit methodologies are (i) prospective (collect data as care is given), (ii) retrospective (collect data after care is given, or (iii) significant event/critical incident.
5. *Collect data* – A realistic and appropriate minimum number of patients should be decided upon. Also, patients should be selected at random, or at least, systematically (quasi-random). “Audit can be distinguished from simple review of patients because it should be regular, include cases selected at random, rather than selected because they are unusual and have systematic criteria for success”(2)(p. 16).
6. *Analyse and compare with target criteria and standards* – data is best stored on a computer database that can run analyses.
7. *Agree and implement changes* – This is often the most challenging aspect of audit. *Feed-back* to the health-care team is usually the initial outcome. Figure 2 below shows various types of changes resulting from audit that can improve patient outcomes. Fraser et al (1998) nominate 5 main outcomes: (i) Education / training (ii) System changes (iii) Reminder systems (iv) Policies / guidelines and (v) Team changes.
8. **Collect further data to evaluate change** – Further data collection occurs using the same methodology to assess whether the changes that have been implemented have worked (Point 7).

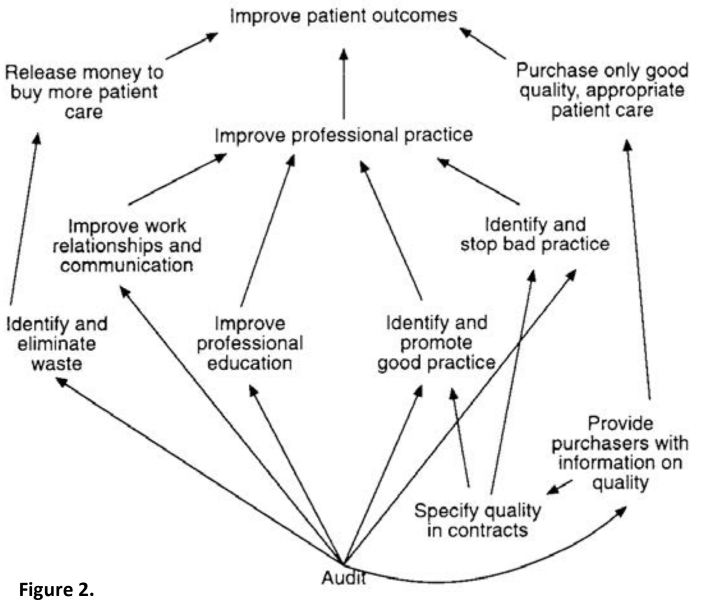


Figure 2.
http://www.emeraldinsight.com/content_images/fig/0620080303001.png

Designing a Questionnaire/Survey

- The questionnaire, or survey (or set of interview questions) (‘the tool’), you design is the central part of your research. The better designed and structured it is, the better responses you can expect from participants.
- A questionnaire or survey differs from an interview in that the participant alone responds to the written questionnaire either on paper or online (some questionnaires are becoming a lot more sophisticated and being presented online), whereas an interview is an interplay between the interviewer and the interviewee and is usually recorded and then transcribed. We will focus on the written questionnaire or survey here.

- You can *design your own* questionnaire *or use one of the many existing* questionnaires or tools (see websites below). Some of these you may need to purchase or get the author's permission to use. Sometimes you may wish to modify or add questions to an already-existing tool.
- If the tool is too long, confusing, repeats itself or not something, which is easy to answer, then participants will not complete it and you will have a lot of 'missing data'. Similarly, if, when interviewing participants, you do not engage with the participant, then you will miss out on a lot of rich information.
- Questionnaires can have different types of responses being sought from participants:

  (i) Yes / no / don't know / can't remember - type responses which participants circle or tick.

  (ii) Ratings e.g. 1 through to 5 from 'very dissatisfied' (1), 'dissatisfied' (2), 'neither satisfied or dissatisfied' (neutral) (3), 'satisfied' (4) or 'very satisfied' (5). You can rate on many other things as well e.g happiness/unhappiness, comfortable/uncomfortable etc. Again, participants circle or tick these responses.

  (iii) Open-ended questions. Where you want the participants to write down information which you hope will give you more detailed or rich information about their experiences.
- Questions should be in clear, easy to understand, lay language (minimise use of technical terms or jargon which the participant is unlikely to understand) and should not be too convoluted or long. Better to ask more simple questions than one long question with multiple parts.
- Always ensure that any questions you ask relate back to one of the research aims (or one of your hypotheses) of your study.
- Always check and re-check your questionnaire when drafting it. It is an important document which is going into the public domain. It is always a good idea for someone else to have a look at it, not only in terms of spelling or grammar, but in terms of how they find doing it as a potential participant. You may wish to pilot your questionnaire to a small group of people first to see if the responses you are getting are what you expect, particularly for open-ended type questions. It is also important to check in case any questions accidentally get left off, particularly after it is formatted or photocopied. It is very frustrating to administer a questionnaire to a lot of people to discover later that a question or even a whole page was missing. This is information (data) you cannot recover.
- Fortunately, there are a lot of existing, validated questionnaires, which can be used (subject to copyright). Useful websites to look for haematology-specific as well as some widely used general questionnaires / resources are listed below.
- **See Assessment tools on the eviQ website for Multiple Myeloma, Leukaemia and Lymphoma: www.eviq.org.au**
- **European Hematology Association's book "Guidelines: Patient-reported outcomes in Hematology", 2012**
- **Functional Assessment of Cancer Therapy Scales (FACT) has general and disease specific questionnaires: http://www.facit.org/facitorg/questionnaires**
- **The European Organisation for the Research and Treatment of Cancer (EORTC) has Quality of Life (QoL) general and disease specific questionnaires: http://groups.eortc.be/qol/**
- **Multinational Association of Supportive Care in Cancer (MASCC) guidelines and tools: http://www.mascc.org/guidelines-and-tools**
- **PROMis (Patient Reported Outcomes Measurement Information System) has several pages of available tools/insturments/surveys/questionnaires: http://www.assessmentcenter.net/documents/InstrumentLibrary.pdf**
- **PROMis also has a page of related resources from other groups:**

http://www.nihpromis.org/resources/resourcehome

- **Useful resource page on QoL issues:** http://qualityoflife.elsevierresource.com/

Below is a sample of a questionnaire with the aim of receiving feedback on this article, and by way of example!

EVALUATION SURVEY
"Newsletter article: Clinical audit and Questionnaire design"

Please complete this evaluation by indicating your response. Please do not mark your name on the evaluation.

For example:

Strongly Agree [✓ **Agree**] **Not Sure** **Disagree** **Strongly Disagree**





1. I feel confident that I understand what a clinical audit is.

Strongly Agree Agree Not Sure Disagree Strongly Disagree

2. I feel confident in knowing how to design a questionnaire.

Strongly Agree Agree Not Sure Disagree Strongly Disagree

3. I found this article useful.

Strongly Agree Agree Not Sure Disagree Strongly Disagree

Thank you!

Forgotten to pay your subscription and want to remain an associate nurse member? Not a problem, call or email now and arrange payment with HSANZ office directly.

Email: hsanz@hsanz.org.au
Ph: 02 9256 5456

Don't forget – 85% of your subscription comes directly to the nurses group. Pay now and remain part of *your* professional group.

With thanks HSANZ NG members.

Answers to Haematology Tea Room Quiz p13.

1. d) All of the above
2. a) Fever, night sweats, weight loss
3. d) All of the above
4. b) Leukaemia
5. Acute Lymphoblastic Leukaemia (ALL), Chronic Lymphoblastic Leukaemia (CLL), Acute Myelogenous Leukaemia (AML), and Chronic Myelogenous Leukaemia (CML)
6. Acute Lymphoblastic Leukaemia (ALL)
7. Hodgkin's Lymphoma
8. Genetically engineered in a laboratory
9. Recombinant Factor VIII (Haemophilia A) replacement clotting factors

Journal Scan: Some light reading

From the Editors: Julija Sipavicius, BMT Nurse Practitioner RMH & Tracy King, Myeloma CNC RPA

Clinical Focus - BMT

As we undertake more and more transplants in the older population (a generational membership I find myself entering!), it is not uncommon to assess and work-up patients with varying degrees of organ dysfunction who are planned to proceed to bone marrow transplantation – both autologous and allogeneic. Two articles recently published in the journal *Biology of Blood and Marrow Transplantation* address and discuss dosage adjustments of the more common preparative conditioning regimes in patients with chronic hepatic and renal dysfunction. To date there have been no clear standard or guidelines on how to manage these patients, and dose adjustments are commonly made on a case-by case basis and clinical expertise at the local level. Both articles aim to provide a guide on optimising dosing for these patient populations, and incorporate a comprehensive overview of the literature in these common conditions.

- Bodge, M.; Culos, K.; Haider, S. et al (2014). Preparative Regimen Dosing for Hematopoietic Stem Cell transplantation in Patients with Chronic Hepatic Impairment: Analysis of the Literature and Recommendations. *Biol Blood Marrow Transplant.* 20: 622-629.
- Bodge, M.; Reddy, S.; Thompson, M. et al (2014). Preparative Regimen Dosing for Hematopoietic Stem Cell transplantation in Patients with Chronic Kidney Disease: Analysis of the Literature and Recommendations. *Biol Blood Marrow Transplant.* 20: 908 - 919.

Useful App: Blood – allows immediate access to full-text articles pre-published in First Edition and Blood for users with subscriptions (personal or institutional). Don’t have a subscription – then you can access abstracts of the articles. Blood is the official journal of American Society of Haematology ASH.

Supportive Care Focus

Optimal management of toxicities associated with treatment is an essential component of care. Two recent publications have focused on updating what we know about the prevention and management of chemotherapy induced peripheral neuropathy (CIPN). The American Society of Clinical Oncology (ASCO) have published their evidenced based clinical practice guideline in the Journal of Clinical Oncology (Hershman, D et al 2014) and the Multinational association of supportive care in cancer (MASCC) Neurologic Complications Study Group (Pachman D et al 2014) have published a summary of best available evidence focusing on what we know about the management for established CIPN. Professional cancer / haematology groups produce a comprehensive range of publications, guidelines and patient resources for health professionals to access and use and I’d encourage you to ‘book mark’ their sites for regular review.

ASCO recent guidelines include:

- Prevention and Management of Chemotherapy-Induced Peripheral Neuropathy in Survivors of Adult Cancers.
- Screening, Assessment and Management of Fatigue in Adult Survivors of Cancer
- Screening, Assessment and Care of Anxiety and Depressive Symptoms in Adults with Cancer www.asco.org

MASCC Guidelines and Assessment tools include:

- Antiemetic guideline and tool
- Mucositis guideline and assessment tool
- MASCC International pain management centre – range of resources
- www.mascc.org Official Journal: Supportive Care in Cancer

- Pachman, D., Watson, J., Lustberg, M. et al (2014). Management options for established chemotherapy-induced peripheral neuropathy. Supportive Care in Cancer. 22:2281-2295
- Hershman, D., Lacchetti, C., Dworkin, R et al (2014). Prevention and Management of Chemotherapy-Induced Peripheral Neuropathy in Survivors of Adult Cancers: American Society of Clinical Oncology Clinical Practice Guideline. Journal of Clinical Oncology. Published ahead of print. April 14 2014. www.jco.org.au

HSANZ NG – Changes to CPD and Hours of Learning from NOVEMBER 2014

As part of your annual renewal requirements haematology nurses registered with the Nursing and Midwifery Board of Australia (National Board) are expected to do a minimum number of continuing professional development (CPD) hours directly relevant to your context of practice.

What is CPD?

CPD is the means in which members of the nursing profession maintain, improve and broaden their knowledge, expertise and competence in their chosen specialty.

How many CPD hours am I required to obtain?

Registered nurses are required to undertake a minimum of 20 hours. Nurse practitioners are required to engage in a minimum of 30 hours – 20 hours as a registered nurse and 10 hours relating to prescribing and administration of medicines, diagnostics investigations, consultation and referral.

How long do I need to keep a record of my CPD, including 'self-directed learning'?

The CPD registration standard does not specify the length of time CPD evidence must be kept, however, the National Board recommends that you keep evidence of CPD, including 'self-directed learning' for a period of three years.

What is the HSANZ NG's current practice?

Our educational activities are currently endorsed by APEC (Authorised Provider of Endorsed Courses) through the Royal College of Nursing, Australia (RCNA). This remains current for the HSANZ Nurses Group until the 22nd November 2014 when our endorsement expires.

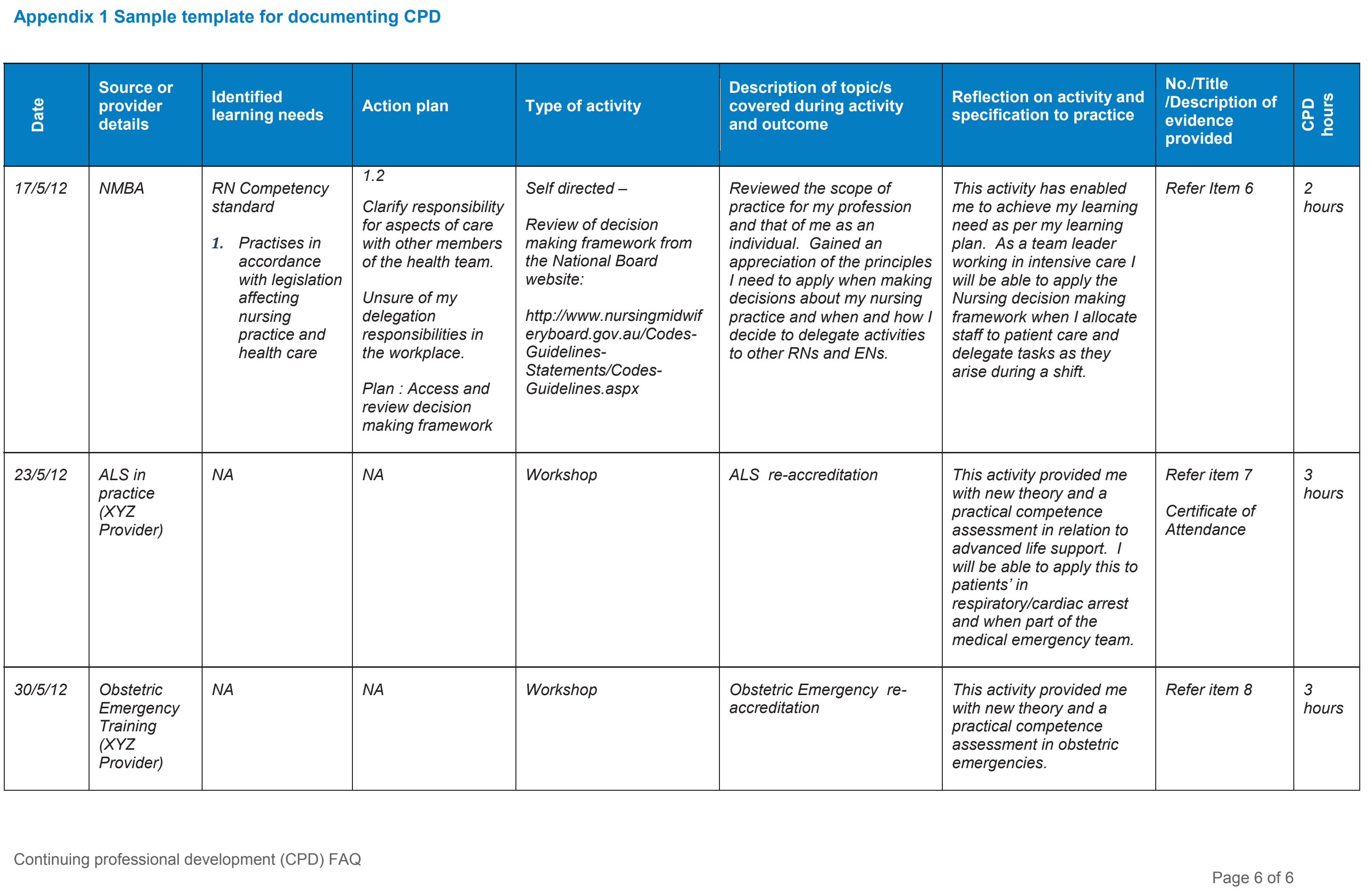
The RCNA's APEC program has now been transitioned to the Australian College of Nursing's (ACN's) Endorsed Course program. This represents some changes that no longer make it practical for the HSANZ Nurses Group to become endorsed for individual events through the ACN.

What will change from November 2014?

You will note that your HSANZ attendance certificate currently states: 'Attendance attracts XX RCNA Continuing Nurse Education (CNE) points as part of RCNA's Life Long Learning Program (3LP)'. From November 2014, this statement will change to the following: 'Attendance at this educational activity represents XX active hours of Continuing Professional

Development in accordance with AHPRA guidelines'. The FAQ page on the Nursing and Midwifery Board of Australia website has a very useful sample template (see template below) that demonstrates how you can document your CPD for AHPRA requirements. The link to the FAQ pages for CPD requirements can be found at the Nursing and Midwifery Board of Australia website. http://www.nursingmidwiferyboard.gov.au/Codes-Guidelines-Statements/FAQ/CPD-FAQ-for-nurses-and-midwives.aspx . Therefore, from November 2014, any attendance at an educational meeting associated with the HSANZ NG will no longer be APEC endorsed (as it has now transitioned to a different type of endorsement with ACN), however, the amount of education time can still contribute to your CPD hours.

If you require any further information please do not hesitate to contact: Jenelle Peppin on Jenelle.Peppin@mh.org.au



Appendix 1 Sample template for documenting CPD

Date	Source or provider details	Identified learning needs	Action plan	Type of activity	Description of topic/s covered during activity and outcome	Reflection on activity and specification to practice	No./Title /Description of evidence provided	CPD hours
17/5/12	*NMBA*	*RN Competency standard* *1. Practises in accordance with legislation affecting nursing practice and health care*	*1.2* *Clarify responsibility for aspects of care with other members of the health team.* *Unsure of my delegation responsibilities in the workplace.* *Plan : Access and review decision making framework*	*Self directed –* *Review of decision making framework from the National Board website:* *http://www.nursingmidwiferyboard.gov.au/Codes-Guidelines-Statements/Codes-Guidelines.aspx*	*Reviewed the scope of practice for my profession and that of me as an individual. Gained an appreciation of the principles I need to apply when making decisions about my nursing practice and when and how I decide to delegate activities to other RNs and ENs.*	*This activity has enabled me to achieve my learning need as per my learning plan. As a team leader working in intensive care I will be able to apply the Nursing decision making framework when I allocate staff to patient care and delegate tasks as they arise during a shift.*	*Refer Item 6*	*2 hours*
23/5/12	*ALS in practice (XYZ Provider)*	*NA*	*NA*	*Workshop*	*ALS re-accreditation*	*This activity provided me with new theory and a practical competence assessment in relation to advanced life support. I will be able to apply this to patients' in respiratory/cardiac arrest and when part of the medical emergency team.*	*Refer item 7* *Certificate of Attendance*	*3 hours*
30/5/12	*Obstetric Emergency Training (XYZ Provider)*	*NA*	*NA*	*Workshop*	*Obstetric Emergency re-accreditation*	*This activity provided me with new theory and a practical competence assessment in obstetric emergencies.*	*Refer item 8*	*3 hours*

Continuing professional development (CPD) FAQ

Page 6 of 6

HSANZ

The Royal Melbourne Hospital

*Advanced Staff Only

Bone Marrow and Haematopoietic Stem Cell Transplants

CPD - 16 hours

Mon 10 & Tue 11 November 2014

8.00 am - 5.00 pm
Charles LaTrobe Theatre
The Royal Melbourne Hospital
Grattan St
Parkville, VIC, 3052

About the Course

The Bone Marrow Transplant short course was developed to meet the learning needs of nurses caring for patients undergoing bone marrow or peripheral stem cell transplantation.
In preparation of the program, we ask that you be familiar with the basic transplant process. To assist you with this please familiarise yourself with the pre readings attached to this flyer on the RMH Nursing Education Website

Topics include

- Overview of Haemopoiesis and Immunosuppression
- The history of Bone Marrow Transplantation
- Tissue Typing and the Bone Marrow Donor Registry
- Clinical Indications for BMT
- Infection in BMT
- Management of BMT recipients including: Complication Management, Oral Management, Total Body Irradiation, Psychosocial Issues, Nutrition, Graft versus Host Disease (GVHD)
- Long term issues
- Apheresis

Program Structure

The program consists of two full day training sessions.

Program Eligibility

The program is open to Registered Nurses, Enrolled Nurses, Medical Staff and Allied Health Staff.

Program Enrolment

The program is limited to 80 participants.

Amenities

For full day courses, lunch and refreshments provided. (Please let course coordinator know of special dietary requirements by 24 October 2014).

To Register

Please download the registration from from the following link:

Http://www.rmh.mh.org.au/nursing-education-short-courses/w1/i1031959/

Registrations close: **Friday, 24 October, 2014**

Registration is from 8am - 8.30am (Mon 10th November)

Program Duration

Course fees

External Applicants:	$350.00
Melbourne Health Employees:	$200.00

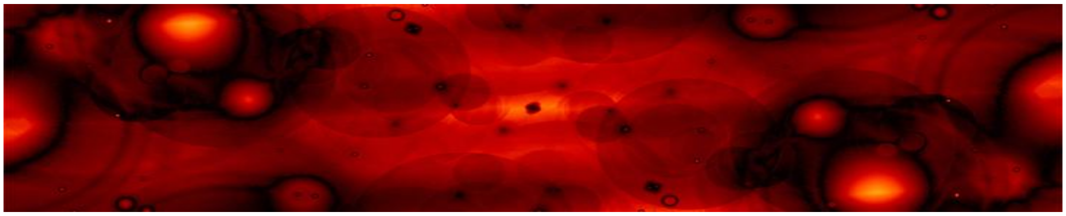
For more information about the clinical content of this course, contact:

Chelsea Victor
Clinical Nurse Educator
Ph: 03 9342 7000 pager: 7343
Email: chelsea.victor@mh.org.au

For registration and payment queries, contact:
Short Course Administration
Ph: 03 9342 4981
Fax: 03 9342 4970
Email: shortcourse@mh.org.au

BONE MARROW TRANSPLANT 2014

The Royal Melbourne Hospital is part of Melbourne Health. ABN 73 802 706 972



Blood & Bone Marrow Transplant Education Day

Wednesday 24th September 2014

Nurses involved in the care of individuals requiring Blood and Bone Marrow Transplantation, are warmly invited to attend the annual education day hosted by Institute of Haematology RPA in collaboration with Cancer Nursing Research Unit and the HSANZ Nurses Group.

VENUE: Kerry Packer Auditorium, RPAH.

TIME: 0800 – 1645 FEE: No charge

SPEAKERS INCLUDE

Professor John Gibson, Haematologist

Dr Nicky Gilroy, Infectious Disease Specialist,

Dr Angela Hong, Radiation Oncologist

Professor Kate White, Cancer Nurse Researcher

Ms Beth Newman, Haematology BMT, Nurse Practitioner

PLEASE RSVP NO LATER THAN THE 17TH SEPTEMBER FOR CATERING PURPOSES

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Attendance attracts 7 RCNA continuing nurse education (CNE) points as part of RCNA's life-long learning program (3LP)

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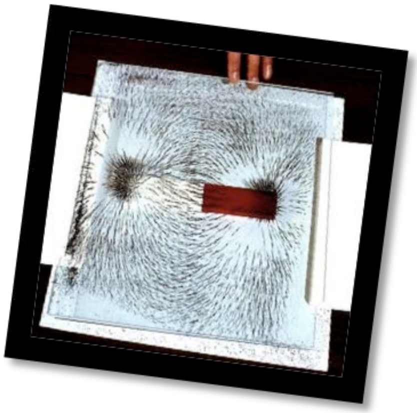
Clinical Trials Corner

'A Chance Finding'

Hayley King
Haematology Research Nurse
Royal Melbourne Hospital, VIC

Hi there, my name is Hayley King and I have taken the baton from Jenelle Peppin as Victorian Trials Corner Correspondent. I work equal hours at the Royal Melbourne Hospital as a Haematology Research Nurse and at Myeloma Australia as Myeloma Support Nurse Manager. I look forward to sharing the Trials Corner with NSW author Bec Meti who I used to share a workplace with in London some years ago.



While clinical trials are most often designed around improving already used compounds into more targeted, less toxic treatments or by applying old science to a new concept, every now and then a scientific breakthrough occurs by chance or by thinking outside the box. This is what I find most interesting about research and my chosen topic this edition. For example the solid tumour treatment, Cisplatin was discovered by Barnett Rosenberg a biophysicist at the University of Michigan, in the 1960s. He thought the process of mitosis in a dividing cell was much like the old school science experiment of creating magnetic field lines by placing iron filings on a piece of paper over a magnet. On further investigation he discovered that inert platinum electrodes inhibit cell division in bacteria. This theory was then successfully applied to sarcomas implanted in rats and the first major chemotherapy drug was born revolutionising the survival rates of many cancers and generating much interest in the use of metal compounds in the treatment of cancer.

In the mid 80s during a time of economic crisis in China, chemotherapy agents were deemed too expensive and alternative treatments were required. Some creative thinking then led to trials of all-trans retinoic acid (ATRA) in the treatment APL. It was discovered that ATRA could enable terminal maturation of leukaemic blasts improving survival rates of APML out of sight.

Then we have the much documented catastrophic effects of thalidomide when given to pregnant women for nausea and insomnia. The interruption of the cellular processes that caused deformed limbs in unborn babies was further researched and has seen thalidomide return to the formulary for a number of conditions. It was first used in patients with leprosy in 1964 when a physician in Jerusalem gave thalidomide to sedate a gentleman to relieve him from his leprosy symptoms of painful nodular lesions, fever and arthritis. He noted dramatic reduction in symptoms which then led to the World Health Organisation (WHO) conducting a double blinded study comparing thalidomide to acetylsalicyclic acid. This found thalidomide to be more effective for skin lesions but not neural and internal lesions. Further studies have also shown thalidomide to be active in numerous skin conditions including Behcet syndrome (blood vessel inflammation), discoid lupus erythematosus and graft versus host disease.

Interestingly in 1997, it was the wife of a myeloma patient who suggested to American haematologist Dr Bart Barlogie that he'd try thalidomide for her cardiologist husband whose myeloma had become refractory to conventional treatments. Unfortunately the drug did not work on this occasion but it did for another patient leading to Dr Barlogie and the University of Arkansas to set up a clinical trial. The results of this trial marked the first successful new myeloma treatment in 30 years.

In more recent years there has been another discovery of somewhat accidental nature involving a potential new treatment for myeloma. Researcher, Dr Jake Shortt at the Peter MacCallum Cancer Centre noticed in 2010 that pre-clinical models of myeloma were responding to the control substance that was devoid of any of the novel agents they were testing. This control substance was N-methyl-2-pyrrolidone (NMP) a solvent used in laboratories for many years for the transportation, storage and delivery of many compounds. NMP is also commonly found in products such as paints, fabrics, medical patches and dental barriers. NMP is thought to have a bi-dimensional approach in the treatment in myeloma in that it affects the growth and survival of the myeloma cell as well as stimulating the immune system to attack.

The well-established nature of NMP has cut development time significantly and a phase I clinical trial is set to open at Peter MacCallum Cancer Centre, Monash Medical Centre and the Royal Melbourne Hospital by the end of this year for relapsed/refractory patients who have failed or are intolerant to bortezomib and lenalidomide. Transplant eligible patients will have already had an autologous stem cell transplant to be eligible. If successful we will see another weapon in the armamentarium against myeloma that is both cost-effective and plentiful.

References:

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- Greenstone, G. June 2011, 'The revival of thalidomide: From tragedy to therapy', BC Medical Journal vol 53 no.5
- Wang, Z. Y. March 2008 'Acute promyelocytic leukemia: from highly fatal to highly curable' Blood vol 111, no. 5
- Ritchie, D., Shortt, J. 'A phase I study of the first in class dual IMiD/bromodomain inhibitor N-methyl-2-pyrrolidone (NMP) in relapsed and refractory multiple myeloma' (Background and research plan paper to the NHMRC)

BLOOD SERVICE RESOURCES FOR HEALTH PROFESSIONALS

OUR TRANSFUSION GATEWAY

transfusion.com.au is our website for health professionals. It's a useful resource for product and practice information as well as a gateway to online learning and transfusion tools and resources.

TRANSFUSION ONLINE LEARNING

Our online learning is easily accessed via the home page of transfusion.com.au Signing in lets you register for sessions and receive certificates for attendance.

Live or online sessions

We offer **Blood Service Fellows Transfusion Rounds**, a **Registrar Transfusion Education Program**, **Transfusion Practice Education Sessions** and an **Under the Microscope** series, available as webinars, with some supported by live events. We support the **RCPA Haematology Advanced Trainee Laboratory Tutorial Program** within our system.

You can also access some recorded sessions of previous Blood Service Fellows Transfusion Rounds and some of our webinars in this area.

Self-paced sessions

Q&A – make sure your transfusion and patient blood management knowledge is up-to-date with quizzes you can take online or have sent to your mobile at intervals of your choice.

Adverse events – an eLearning module supports your knowledge, and the app and lanyard card assist with decision-making at the bedside.

RhD eLearning – supports safe and appropriate administration of RhD immunoglobulin by health professionals.

Irradiated products – improve your awareness of transfusion-associated graft versus host disease (TA-GvHD) and its prevention.

TRANSFUSION RESOURCE CENTRE

Our **Transfusion Resource Centre** at transfusion.com.au is a library where you can search for all of the information and tools we offer on transfusion.

Patient Blood Management Committee Handbook is a guide for PBMC members that suggests format and activities for meetings and is rich with resources.

BCI – our blood component information booklet. Available in print or as an app, the BCI is currently being revised for 2014.

Flippin' Blood is a bedside flipchart to assist with correct transfusion practice for staff who do not transfuse regularly.

High Ferritin is the app that enables doctors to seamlessly refer patients for therapeutic donation with the Blood Service.

Pack Check teaches correct practice for checking a blood component pack before transfusion, complete with student exercises and case studies.

FOR PATIENTS

mytransfusion.com.au is our website for patients who might need to have a transfusion. The site includes downloadable fact sheets, information about iron deficiency anaemia, risk and consent.

FOR EVERYONE

Fact Sheets explain blood products, processes and uses for people without a health, science or medical background.

Blood typing is an app designed for science students or people who are curious to find out how blood type is identified and the consequences of mismatch.

How much blood? is an app that lets the user input their height and weight to calculate how much blood they have, then breaks this down into components and explains their function.

KEEP INFORMED

To receive our bimonthly enewsletter **Transfusion News**, send an email to transfusion@redcrossblood.org.au

You can also follow **@TransfusEd** on twitter for updates about transfusion education events, resources and news from in and around the transfusion community.

Australian Red Cross
BLOOD SERVICE

Regional Round up!

HSANZ NG – regional groups are made up of nurses willing to contribute their time and energy to improve the care of those with a haematological condition within Australia and New Zealand. They do that by hosting educational meetings that not only give us all an opportunity to learn, but also to network with other like-minded nurses. These groups and meetings are only possible with the generous support of pharma but also, by the contributions, drive, and *engagement of us all*. If you have the time to contribute on a local committee, or offer some ideas for meeting topics, speakers, perhaps even present your work yourself; then we would all love to hear from you. Please take the time to get involved with your local group in some way.

North Island, New Zealand

Catherine Wood

Winter is starting to bite in the lower North Island – the southerly has been with us for a few days now and it has been cold. The lower North Island has run two education sessions so far this year and there are another two to come. The first session for the 2014 year was held in Palmerston North. Dr Elayne Knottenbelt gave a very good overview of bone marrow biopsies. The second session was a very successful presentation in Wellington from Professor John Carter about ALL. The two evenings were generously sponsored by Gilead and Janssen. Dates and topics for remaining education evenings for the 2014 year are as follows:

Date	Location	Topic
13th August	Palmerston North	NHL
12th November	Wellington	Bone marrow biopsy and intrathecal chemotherapy

The education evenings are popular and there are limited places available, so get in quickly! If anybody would like further information about any of these meetings or would like to attend then please feel free to get in touch with me. I can be emailed at Catherine.Wood@ccdhb.org.nz

South Island, New Zealand

Jane Worsfold

The HSANZ nurses group from the South Island Bone Marrow Transplant Unit at Christchurch Hospital hosted a haematology quiz night to raise funds to assist Wendy Jar (CNS) to attend HAA in Perth this coming October. This proved very popular & a fun evening was had by both medical & nursing staff. Special thanks has to go to Eleanor Williams for arranging questions & a quiz master. After an upcoming quarterly meeting, the HSANZ group will be planning an education session for "Lymphoma Awareness Day" where the satellite centres from around the South Island will be invited to link in to a video conference. The LBC New Zealand annual winter workshop is due again in July & attending nurses gain education hours. The theme is "AYA" & Kate Thompson from Melbourne will be the guest speaker. Jane.Worsfold@cdhb.health.nz

Victoria

Jenelle Peppin

As we quickly approach the second half of the year, the Victorian Nurses Group is in full swing! In keeping with our Memorandum of Understanding with the Cancer Nurses Society of Australia (CNSA), our second meeting for the year was held in conjunction with our colleagues from CNSA. We were thrilled to have Consultant Medical Oncologist and National Breast Cancer Foundation Practitioner Fellow, Professor Kelly-Anne Phillips from Peter MacCallum Cancer Centre presenting 'An Overview of Medical Prevention of Breast Cancer – Implications for Hodgkin's Disease Survivors '. The session was hotly sought-after with attendance of 40 nurses and a waitlist of 30! The feedback from the event was overwhelmingly positive. We hope to generate just as much interest with our next educational meeting for the year. We are delighted to have Dr Mary Ann Anderson presenting 'New Treatments for Leukaemias and Lymphomas'. We look forward to seeing many of you at this meeting, as well as subsequent meetings to come. Finally, for those of you who are interested in attending the HAA Conference in Perth this year, it is my pleasure to advise that the Victorian Nurses Group will be providing four HAA Grants, so I encourage you to look out for these shortly. Jenelle.Peppin@mh.org.au

Tasmania

Gillian Sheldon-Collins

Following on from our successful educational dinner in March, Amgen have generously offered to support another dinner in November. We are still working in the program but it will interest everyone and we hope to have some dynamic local speakers. Once again this will be in collaboration with CNSA. The Clinical Nurse Educators at the RHH held a successful Haematology Study Day earlier this year, which was very well attended with a varied audience. Another one is being planned for September.

SAVE THESE DATES

- 11th September 2014 RHH Advanced Haematology Study Day
- 7th November 2014 Combined HSANZ NG and CNSA Educational Dinner, Hotel Grand Chancellor

Gillian.sheldoncollins@dhhs.tas.gov.au

New South Wales/ ACT

Tracy King

We welcome Maple Rose – Grainne's (secretary) beautiful little baby girl and HSANZ NG member in the making. Maple has already attended planning meetings and contributes in her own special way – you know what I mean Maple!!

NSW / ACT co-hosted 'Making Sense of Myeloma' – an education day for nurses with Celgene in Sydney with 96 nurses in attendance and more on the wait list. A program combining clinical updates from Dr Cecily Forsyth and Prof Joy Ho was complimented by an expanded case study presentation with expert panel. Prof Kate White chaired a panel including Sue McConaghy (Clinical Psychologist); Jacqui Jagger (Haematology Care Coordinator); Tracy King (Myeloma CNC) & Suzanne Grant (Acupuncturist). We were particularly pleased that Prof Joy Ho, President of HSANZ was able to join us. Celgene's ongoing support of Haematology nurse education in NSW / ACT is established and was critical the success of the day. With the success of the MM day we aim to host a disease focused event each year. Meetings ahead include Wollongong on 14th August Dr Desai presenting 'Shades of Grey'; a combined BMT education day on 24th Sept with RPA Institute of Haematology and a post HAA dinner meeting in Sydney mid November – watch out for dates. Spaces at our dinner meetings are restricted, and we appreciate your understanding if you are unable to attend a specific meeting. The organising committee try hard to offer a fair number of places per unit but reply on units and as such, restrict numbers from any one unit. The only way to expand numbers is to pass on the cost of meetings to those attending and we feel this would be prohibitively expensive. NSW / ACT has been thrilled to bring sponsorship opportunities to attend HAA to members in its region as well as junior nurses in haematology around Australia. We have been overwhelmed by applications that fuel our energy to try even harder next year to obtain even more support. Over 32 applicants were received for the junior category alone!

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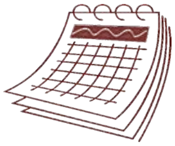

Conference Calendar

Date	Conference	Details
September 2014		
5th – 6th September	**BMT Network Forum**	Sydney, Australia http://www.aci.health.nsw.gov.au/events/bmt-network-clinicians-meeting-2014 Registrations open
October 2014		
19th – 22th October	**HAA ASM**	Perth, Australia Abstract submission closed Registration open: early bird deadline 12.09.14 http://www.haa2014.com/
November 2014		
11th – 14th November	**ALLG Meeting**	Sydney Australia http://www.allg.org.au/events.html
December 2014		
2nd – 4th December	**COSA**	Melbourne, Australia Abstract submission open: closes 13.08.14 Registration open: early bird deadline 05.09.14 http://www.cosa2014.org/
6th – 9th December	**American Society of Hematology (ASH)**	San Francisco, USA Abstract submission and registration not yet open http://www.hematology.org/meetings/annual-meeting/
February 2015		
6th – 7th February	**Flinders Survivorship Conference**	Adelaide, South Australia Abstract submission open: deadline 07.11.14 Registration open: closes 07.11.14 http://www.survivorship2015.org/registration/
11 – 15 February	**BMT Tandem Meeting**	San Diego, CA, USA Abstract submission open: deadline 09.10.14 Registration opens 01.08.14 http://www.cibmtr.org/Meetings/Tandem/Pages/index.aspx
March 2015		
22th – 25th March	**EBMT**	Istanbul, Turkey Abstract submission open Sept 2014 Registration opens: European autumn 2014 (no specific details yet) http://www.ebmt2015.org/

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