



# NURSE NEWS

Volume 3 • 2019

## Welcome to the first edition of Nurse News for 2019!

Lymphoma Australia's Nurse News aims to keep nurses with a special interest in lymphoma up to date with all aspects of lymphoma care both locally and from around the world.

We hope that you all had a wonderful Christmas and New Year! Lymphoma Australia have been busy preparing for an even bigger year for 2019! We are planning nurse and patient education events all around Australia, education webinars and we will be attending all of the lymphoma meetings/conferences and visiting hospitals to connect with more nurses. It is an exciting time in the lymphoma space, and we plan to keep you all well informed of the latest news both locally and from around the world.

We now have over 500 nurses in the Lymphoma Nurse Special Interest Group, where the feedback that we have received is fantastic! Thank you! Please let us know how we can continue to help support you, so as to provide the best care for lymphoma patients and their families. Nurses play a crucial role in ensuring that patients receive the best care to improve their experience during a difficult time.

If you have lymphoma information that you would like to share, if you would like to set up a meeting with Donna, or wish to order resources for your team or hospital, please email us at [enquiries@lymphoma.org.au](mailto:enquiries@lymphoma.org.au) or [donna.gairns@lymphoma.org.au](mailto:donna.gairns@lymphoma.org.au) or phone 1800 953 081.

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# The Development of *Lymphoma* Survivorship Services in WA

Dr Karen Taylor works as a Nurse Educator in the Western Australia Cancer and Palliative Care Network at Sir Charles Gairdner Hospital in Perth, who recently completed her PhD.

She is passionate about improving outcomes for lymphoma patients who have transitioned into the survivorship phase and recently completed her PhD on the subject.

The development of lymphoma survivorship services in Western Australia (WA) began with a focus group study in 2014. This research showed many long-term survivors of lymphoma wish they had been given the opportunity for an end of treatment appointment as they felt this would have helped them transition back into life after cancer treatment better.

I wanted to focus on the supportive care needs of lymphoma patients after they had completed treatment and encourage healthy lifestyle behaviours, so I developed a nurse-led lymphoma survivorship model of care as part of my PhD research. This study was a pilot randomised controlled trial at Sir Charles Gairdner Hospital in Perth WA.

The intervention comprised 3 face to face appointments over 6 months, delivery of tailored resources and an individualised survivorship care plan and treatment summary (SCPTS) I had developed for this cohort. I shared the SCPTS with participants GPs. I used measures that assessed survivorship unmet



Dr Karen Taylor

needs, distress, adjustment to cancer and patient empowerment.

Qualitative results from this study indicated a positive experience in the intervention and the individualised SCPTS really resonated with patients as a way to move forward after treatment completion. GPs were evaluated on how they had used the SCPTS and the majority confirmed it was a useful tool to guide future follow-up.

Quantitative results showed intervention participants reported less unmet needs, less distress and more empowerment by study completion compared with the control (usual care) group. I found a tailored SCPTS may promote self-management and an increase in GP engagement.

The research has ended however I am hoping that I can work with the hospital to ensure the SCPTS is seen as a priority for patients and an end of treatment appointment by an experienced nurse becomes a part of routine care.

**Karen.Taylor@health.wa.gov.au**

If you would like to read more about my study, please see the following publications:

- Taylor, K., Chan, R.J. & Monterosso, L. (2015). Models of survivorship care provision in adult patients with haematological cancer: An integrative literature review. *Supportive Care in Cancer*, 23(5), 1447-1458
- Taylor, K., & Monterosso, L. (2015). Survivorship care plans and treatment summaries in adult patients with hematologic cancer: An integrative literature review. *Oncology Nursing Forum*, 42(3), 283-291
- Taylor, K., & Monterosso, L. (2016). Systematic review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors. *The Australian Journal of Cancer Nursing*, 17(1), 6-12
- Taylor, K., Joske, D., Bulsara, M., Bulsara, C., & Monterosso, L. (2016). Protocol for Care After Lymphoma (CALy) trial: A phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care. *BMJ Open*, 6(e010817), 1-10
- Taylor, K., Bulsara, M., & Monterosso (2018). Test-retest of the Short Form Survivor Unmet Needs Survey (SF-SUNS). *Asia-Pacific Journal of Oncology Nursing*, 5(2), 165-171
- Taylor, K., Monterosso, L., & Bulsara, C. (2018). Qualitative results from a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care. *European Journal of Oncology Nursing*, 35, 9-14
- Taylor, K., Chivers, P., Bulsara, C., Joske, D., Bulsara, M., & Monterosso, L. (2019). Care After Lymphoma (CALy) trial: A phase II pilot pragmatic randomised controlled trial of a nurse-led model of survivorship care. *European Journal of Oncology Nursing*, in press
- Monterosso, L., Taylor, K., Platt, V., Lobb, E., Krishnasamy, M., Musiello, T., Bulsara, C., Stratton, K., & Joske, D. (2017). A qualitative study of the post-treatment experiences and support needs of survivors of lymphoma. *European Journal of Oncology Nursing*, 28, 62-68

## Meet the *Lymphoma Australia* staff members

For those who are new to Lymphoma Australia, I would like to introduce you to our current team members:

**Sharon Millman** CEO  
**Melissa Simpson** General Manager – National Marketing and Fundraising

**Donna Gairns** Lymphoma Care Nurse Consultant  
**Sharna Moloney** Lymphoma Care Nurse Consultant  
**Carol Cahill** Community Support Manager  
**Josie Cole** Fundraising Manager

# Spotlight on: Mantle Cell Lymphoma (MCL)

Mantle cell lymphoma (MCL) is a rare, B-Cell Non-Hodgkin Lymphoma (NHL) that most often affects men over the age of 60.

The disease may be aggressive (fast growing) but it can also behave in a more indolent (slow growing) fashion in some patients. MCL comprises about 5-10% of all NHLs. The disease is called “mantle cell lymphoma” because the tumour cells originally come from the “mantle zone” of the lymph node.

About 85% of patients with MCL have a characteristic genetic change in the developing B-Cells where two chromosomes 11 and 14 break and join together with each other. This is called a ‘translocation’ and causes the cells to produce too much of a protein called cyclin D1, which instructs the cells to divide uncontrollably. Excess amounts of Cyclin D result in uncontrolled growth of mantle zone cells which can lead to mantle cell lymphoma (MCL).

Most commonly the first sign of MCL is a painless lump that is rapidly growing in the neck, arm pit or groin that is caused by the swelling of the lymph nodes due to the presence of the lymphoma. MCL can involve other sites of the body, these sites may include the spleen, marrow and blood, the lymph nodes in the throat (tonsils and adenoids), the liver, or the gastrointestinal tract. MCL commonly affects the bowel, and people may have a feeling of fullness in the abdomen or even diarrhoea. Other symptoms may include night sweats, fevers, unexplained weight loss, nausea, and tiredness.

## know your subtype



The type of treatment selected for a patient with MCL depends on many factors, including the stage of disease, the age of the patient, and the patient’s overall health. For the subset of patients who have a indolent MCL and do not yet have symptoms the treatment is often Watch and Wait or “active surveillance” where the patient is monitored until they have symptoms or the MCL has progressed. The majority of cases they are treated as a high-grade lymphoma and will require treatment. Initial treatment approaches include combination chemotherapy, typically in combination with or without a monoclonal antibody called rituximab (Rituxan),

The most common regimens are: R-Hyper CVAD, R-CHOP, and F+CR. Elderly people or those not well enough to endure the side effects of combination chemotherapy may be given single drug treatments such as chlorambucil, cyclophosphamide and fludarabine+, most commonly given in tablet form.

Other therapies include radiotherapy; and stem cell transplants (autologous or allogeneic). Treatment is often successful initially, however relapses are common. New treatments for MCL are being researched all the time with such drugs as temsirolimus, bortezomib and lenalidomide being investigated in clinical trials in some Australian centres.

 <https://bit.ly/2GuFXHD>

# Blood 2018 – Brisbane, October 21st-24th

Blood 2018 was held in Brisbane in October, that was a very successful and included many great presentations from haematology nurses from around Australia and NZ. Congratulations to the organising team and to those who presented. It was wonderful to speak with many of you during the conference at the Lymphoma Australia stand and various sessions.

Thank you again to all who attended the Nurse Education Breakfast, hosted by Lymphoma Australia. Dr Jason Butler presented “The modern approaches for the treatment and management of lymphoma”. Jason discussed how diagnosis and treatment for lymphoma patients has changed since WHO reclassified lymphoid neoplasms in 2016 and current management of lymphoma.



Dr Jason Butler (Clinical Haematologist RBWH) presenting at Lymphoma Australia Nurse Education Breakfast at Blood 2018

Thank you for the wonderful feedback and we plan to bring more education events to nurses this year. For those who missed out we will be adding the presentation video to our website soon and I will let you know once posted.

## Prof Simon Rule visits Brisbane

Lymphoma Australia and Janssen were fortunate to host a patient education event and live webinar during the Blood2018 conference on October 23rd. Professor Simon Rule from the United Kingdom gave a special presentation about the latest treatments for follicular and mantle cell lymphoma. Special thanks to Dr Jason Butler, Lymphoma Australia Board member to MC the event. The filmed education event is available to watch.



(Photo: Dr Michael Aitkenhead, Senior Medical Advisor Haematology - Janssen; Sharna Moloney, Lymphoma Care Nurse Consultant; Dr Jason Butler; Prof Simon Rule; Donna Gairns, Lymphoma Care Nurse Consultant)

 <https://bit.ly/2DJflyN>



# Nurses Face Fear of Heights to Support *Lymphoma* Patients

A passionate group of nurses from Fiona Stanley Hospital will face their fear of heights by abseiling 40-storeys to raise money for Lymphoma Australia. The team from Ward 7D will descend down WA's highest building, the QV1 on Saturday 13 April

Clinical Nurse Educator Annita House said "The group was aiming to raise \$10,000 in support of Lymphoma Australia. Taking on this challenge will help to ensure specialist Lymphoma care nurses are available wherever they are needed. This is an organisation close to our hearts and we wanted to do our bit to raise awareness while also challenging ourselves."

The Fiona Stanley Team have already fundraised over \$2500 and over the next few weeks, will host a fundraising bake sale and sausage sizzle



to help raise money. If you would like to support this caring group of nurses you can make a donation online to help them reach their target

Lymphoma Australia is touched to see such a display of support from the nurses at Fiona Stanley Hospital. We wish the team well and think they are very daring taking on the 40 story abseil. We look forward to sharing an update and photos from the day.

## Fertility preservation for young *Lymphoma* patients

Chemotherapy and radiotherapy for the treatment of lymphoma can also affect fertility. For many young people having children may be the last thing they want to think about right now. But it is important to discuss their fertility with a specialist who can help them to understand the long-term effects of their treatment. They can discuss the options that are available before starting cancer treatment and the follow up after treatment.

Lymphoma Australia were pleased for A/ Prof Kate Stern, a leading specialist in fertility preservation for people undergoing cancer

treatment in Australia, to speak to us about what is fertility, fertility preservation and the options available to young patients receiving treatment for lymphoma. Kate heads the fertility preservation at Melbourne IVF and The Royal Women's Hospital in Melbourne. The information provided in this video will help patients and health professionals to understand fertility preservation and to help make informed decisions.



<https://bit.ly/2UYS7M5>

# Upcoming Events:

Upcoming dates to keep on your calendar



## Australian Leukaemia Lymphoma Group (ALLG)

**Date:** 7 – 10 May 2019  
**Venue:** Hilton Sydney  
**Registration:** [www.allg.org.au](http://www.allg.org.au)

## Lymphoma Nurse Education Forum – Sydney

Hosted by Lymphoma Australia & ALLG

**Agenda:** TBC  
**Date:** Tuesday 7 May 2019  
**Venue:** Hilton Sydney  
**Time:** 9 – 11 am  
**RSVP:** [donna.gairns@lymphoma.org.au](mailto:donna.gairns@lymphoma.org.au)

## 2019 Cancer Nurses Society Australia (CNSA) 22nd Annual Congress, Melbourne

**Date:** 20 – 22 June 2019  
**Venue:** Melbourne Convention and Exhibition Centre  
**Registration:** [www.cnsa.org.au](http://www.cnsa.org.au)



**REGISTER NOW!**

**BRISBANE 10 MARCH | MELBOURNE 23 MARCH  
SYDNEY 31 MARCH | PERTH 7 APRIL**

# We would like to hear from you!

In upcoming editions of "Nurse News" we would like to highlight the great work that lymphoma nurses are doing around Australia. We would like to hear from you by providing a short piece (200-300 words) about your nurse role, a colleague, the cancer service you work within, projects, patient work, presentations, education days, achievements or clinical trials that you are working with. Contact Donna, [donna.gairns@lymphoma.org.au](mailto:donna.gairns@lymphoma.org.au)



## Resources & Fact Sheets

We continue to add to our range of resources and fact sheets that are available to download and print from our website. We can also send you a supply of the books and fact sheets for your patients by emailing [enquiries@lymphoma.org.au](mailto:enquiries@lymphoma.org.au)

These free resources are designed to better inform patients on a wide range of topics including detailed information about lymphoma subtypes, clinical trials, side effects and survivorship. They are also good for revision for health professionals wanting to know more.



## Thank you!

Thank you for supporting Lymphoma Australia and being a part of the Lymphoma Nurse Special Interest Group. We are striving to increase membership and grow our services for you. We would like to encourage you to invite your colleagues to join. Please do not hesitate to contact me if you have any questions or suggestions.

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Join our dedicated closed Facebook group for patients and carers by searching **Lymphoma DOWN UNDER**

For more information visit [www.lymphoma.org.au](http://www.lymphoma.org.au)

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