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MPN Matters Issue 25 - June 2024



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## MPN MATTERS ISSUE 25 - JUNE 2024





## **A first for MPNs in Australia – Australian Optimal Care Pathways for MPNs released**

In late May, the Leukaemia Foundation and Cancer Council released Optimal Care Pathways (OCPs) for MPNs. This is the first time Australian guidelines for MPNs have been released. They have been endorsed by state and territory governments.

These OCP guides are for healthcare professionals, patients, carers, and anyone affected by cancer or involved in cancer care. They describe what optimal care for MPNs should look like. Their aim is to improve patient outcomes by ensuring that all people diagnosed with cancer receive the best care, irrespective of where they live or receive cancer treatment.

## Each OCP is made up of three documents-

### 1) The guide for patients and their families:

[‘Your guide to best cancer care, a version of the OCP specifically designed for patients, carers and their families.’](#)

This patient guide is also [available in several languages](#). \*

(\*click on the grey shaded box that says PDF available for download in your language.)

### 2) and 3) OCP guides for healthcare professionals, including:

- The full OCP, and
- A short quick reference guide which summarises the OCP

You are able to readily access the OCPs for healthcare professionals [HERE](#).

We recommend the patient guide, as it helps to ensure that you are as informed as possible about your care.

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## Launch of version 2 of the Australian Cancer Atlas



*Professor Peter Baade launching the Australian Cancer Atlas v2*

The MPN AA is delighted to showcase the just released version 2 of the Australian Cancer Atlas.

The atlas shows how the impact of all cancers vary substantially depending on where Australians live. Across all cancer types, the consistent pattern is that Australians living in regional and remote areas experience poorer survival than those living in urban areas. MPN survival data appears to be in line with this trend.

Cancer Council Queensland's Professor Peter Baade explains "The atlas shows which areas have above-average risk factors for cancer, which areas have low screening or testing rates, higher rates of cancer diagnoses, and which areas have poorer survival rates."

The MPN AA remains concerned about the apparent disparities in MPN incidence across the country. We believe some of these differences could be due to inconsistencies in reporting MPNs to cancer registries. There have been efforts in the last few years to improve reporting of MPNs, so more recent data

may see MPN incidence become more consistent across the country. If not, the reasons for such disparities in incidence will need to be closely examined.

Similarly, the apparently different survival rates of MPN patients will need to be interrogated and researched.

The Leukaemia Foundation has advised it will be collaborating with the Atlas team and interrogating the data to inform research and better understand the impact of blood cancer across the country.

**MPNs are listed as “classic MPNs” in the atlas. You may wish to follow the visual explainers. It is available [HERE](#).**

For further information and discussion about the MPNs in the atlas, see [HERE](#).

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## Ruxolitinib and risk of non-melanoma skin cancers

Like any medication, monitoring of side effects is always ongoing. Since ruxolitinib has been available to patients, monitoring of side effects has identified in some studies a potential increase in non-melanoma skin cancers. No cause and effect relationship has been proven, particularly as many patients on ruxolitinib have previously been on hydroxyurea.

However, more recently, haematologists in the UK have been highlighting the need for vigilant regular skin checks for patients on ruxolitinib. In 90 patients they studied with NMSCs they found '*Nonmelanoma skin cancers (NMSCs) in ruxolitinib-treated patients with myeloproliferative neoplasms behave aggressively, with adverse features and high recurrence.*' They have stated that '*Vigilant skin assessment, counseling on NMSC risks, and prospective ruxolitinib-NMSC studies are crucial.*'

[Here is an article from the MPN Research Foundation website which includes details of the study.](#)

As Australians in general have a higher incidence of both melanoma and non-melanoma skin cancers, we wanted to bring this issue to your attention. **So if**

**you're taking ruxolitinib, we recommend vigilant and regular skin checks.**

Our ruxolitinib treatment leaflets, including translated versions (Arabic, Chinese and Vietnamese) have been updated to reflect these findings [HERE](#).

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## Recipe – Thai coconut pumpkin soup



*Image: Thai pumpkin soup with herb garnish*

This recipe is simple but delicious. It is based on a Donna Hay recipe with a couple of tweaks. While you may be tempted to add extra vegetables such as potato, it is most delicious when just pumpkin is used.

### Ingredients

- 1 tablespoon red curry paste
- 1 kg pumpkin (such as Kent variety), peeled and chopped
- A couple of lime leaves (optional)
- A couple of lemon grass stalks (optional)

4 cups chicken or vegetable stock

400ml coconut milk

Fresh coriander or any herb (or even a sliver of chilli) to garnish.

### **Method**

In a large saucepan fry curry paste over medium heat and cook for half to one minute.

Add peeled and chopped pumpkin, stock, lime leaves and chopped lemongrass and cook until pumpkin tender.

Blend with a stick blender.

Add coconut cream and cook for a couple of minutes before serving.

Sprinkle with any fresh herb or even a sliced chilli to garnish.



## **Leukaemia Foundation upcoming events**

The Leukaemia Foundation runs regular online support groups.

### **1. Evening Blood Cancer virtual Support Group - 'Self Care'**

**18 June 2024, 7.00pm - 8.30pm (Qld/Vic/Tas/NSW/ACT)**

This topic is about self care. The Leukaemia Foundation advises that 'The diagnosis of blood cancer is 'a marathon, not a sprint'. Taking care of ourselves & others is a key ingredient in how one paces themselves for this 'marathon'.

Group sizes are limited so registration is essential.

To register and for more information - see [HERE](#).

### **2. Watch and Wait Blood Cancer virtual Support Group - 'Self Care'**

**27 June 2024, 6.30pm - 8.00pm (Qld/Vic/Tas/NSW/ACT)**

This group is for 'watch and wait' blood cancer patients.

Group sizes are limited so registration is essential.

To register and for more information - see [HERE](#).

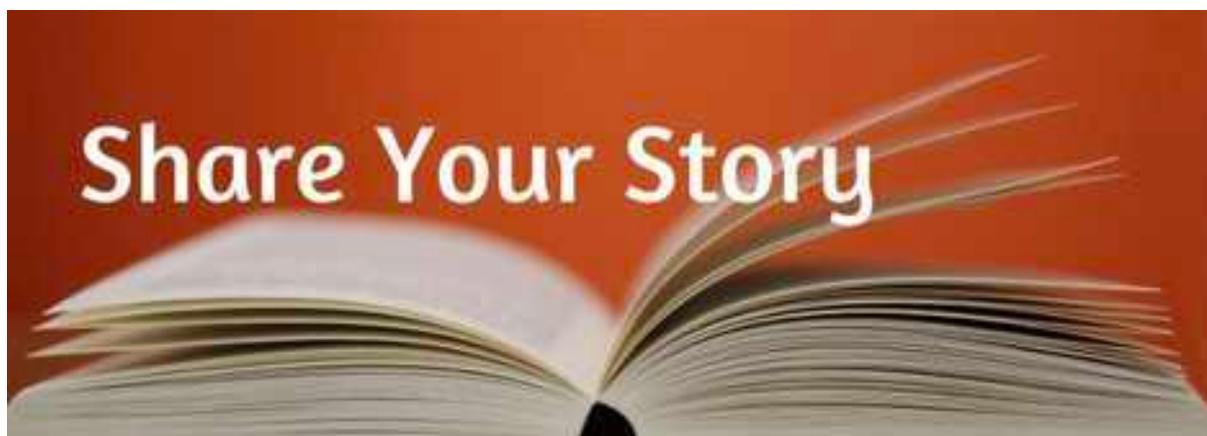
### **3. Webinar - Complementary Therapies: The role of mindfulness in blood cancer 27 June 2024, 11.00am-12.30pm (QLD / VIC / TAS / NSW / ACT)**

In this webinar, you will learn about mindfulness practice and how it can benefit your daily life while living with blood cancer / blood disorder. There will be an opportunity to take part in a short, guided mindfulness exercise to gain an insight into what it is all about.

Extensive studies have shown mindfulness has immense value managing some of the emotional and physical symptoms of blood cancer and treatment side effects e.g. depression, anxiety, pain and fatigue.

To register and for more information - see [HERE](#)

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To help raise awareness of Myeloproliferative Neoplasms and to support other newly diagnosed MPN patients, we are seeking patient stories for the MPN Alliance Australia website. If you feel you would like to share your MPN journey, we would be very pleased to hear from you via our [Contact email](#)

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**Send us an email**

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