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MPN Matters Issue 16 - September 2021



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# MPN MATTERS

## ISSUE 17 - DECEMBER 2021



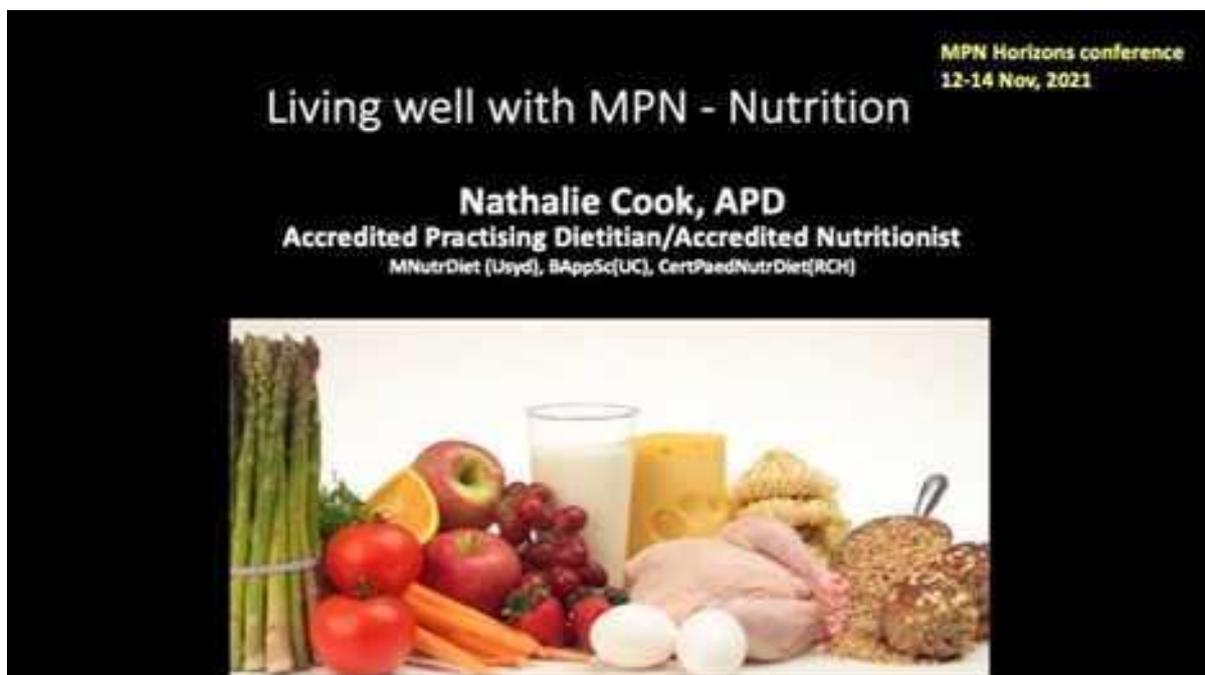


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### **Recent MPN Alliance Australia Activities**

We have created this graphic to show what MPN AA has been doing to improve the lives of Australian MPN patients. There has been a lot of rewarding work behind the scenes, and it has been our privilege to support the MPN community.

<p style="text-align: center;"><b>Advocacy</b></p> <ul style="list-style-type: none"> <li>• Partner with Leukaemia Foundation / Rare Cancers Australia / Rare Voices Australia</li> <li>• Contribute to National Action Plan for Blood Cancer</li> <li>• Support Leukaemia Foundation campaign on equity of access of medical care</li> <li>• Lobbied for continued access to Pegasys &amp; novel MPN therapies, and increased diagnostic services</li> <li>• Work with state and territory cancer registries to improve MPN reporting</li> </ul>	<p style="text-align: center;"><b>Patient Education &amp; Support</b></p> <ul style="list-style-type: none"> <li>• Ongoing attendance at virtual patient conferences</li> <li>• Provision of MPN wallet cards for patients</li> <li>• Facilitate Canberra MPN Walking Group</li> <li>• Keep MPN AA Website up to date</li> <li>• MPN AA partner with Leukaemia Foundation in presenting MPN patient webinar</li> <li>• One-on-one patient phone and email support</li> <li>• MPN AA Newsletters</li> </ul>
<p style="text-align: center;"><b>International MPN Networks</b></p> <ul style="list-style-type: none"> <li>• Serve on the MPN Advocates Network Steering Committee</li> <li>• Participate in organisation of MPN Horizons conference</li> <li>• Team members act as host and expert presenters</li> </ul>	<p style="text-align: center;"><b>Work with Australian MPN Researchers</b></p> <ul style="list-style-type: none"> <li>• Donated \$10k to Australian MPN Spatial research</li> <li>• Australian MPN statistics now included in the Australian Cancer Atlas as a result of MPN AA advocacy</li> <li>• Team members act as Consumer representatives for Australian MPN Researchers</li> </ul>



MPN AA team member Nathalie Cook was an expert presenter at the 2021 MPN Horizons Conference. This conference is organised annually by the global MPN Advocates Network. MPN AA team member Ken Young is a Steering Committee member of the MPN Advocates Network, and co-chaired this meeting.

[Watch Nathalie's presentation](#)

You can view all the videos from the Conference  
here: <https://vimeo.com/showcase/9094838>

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The Canberra MPN walking group enjoying the fresh air at Weston Park recently.

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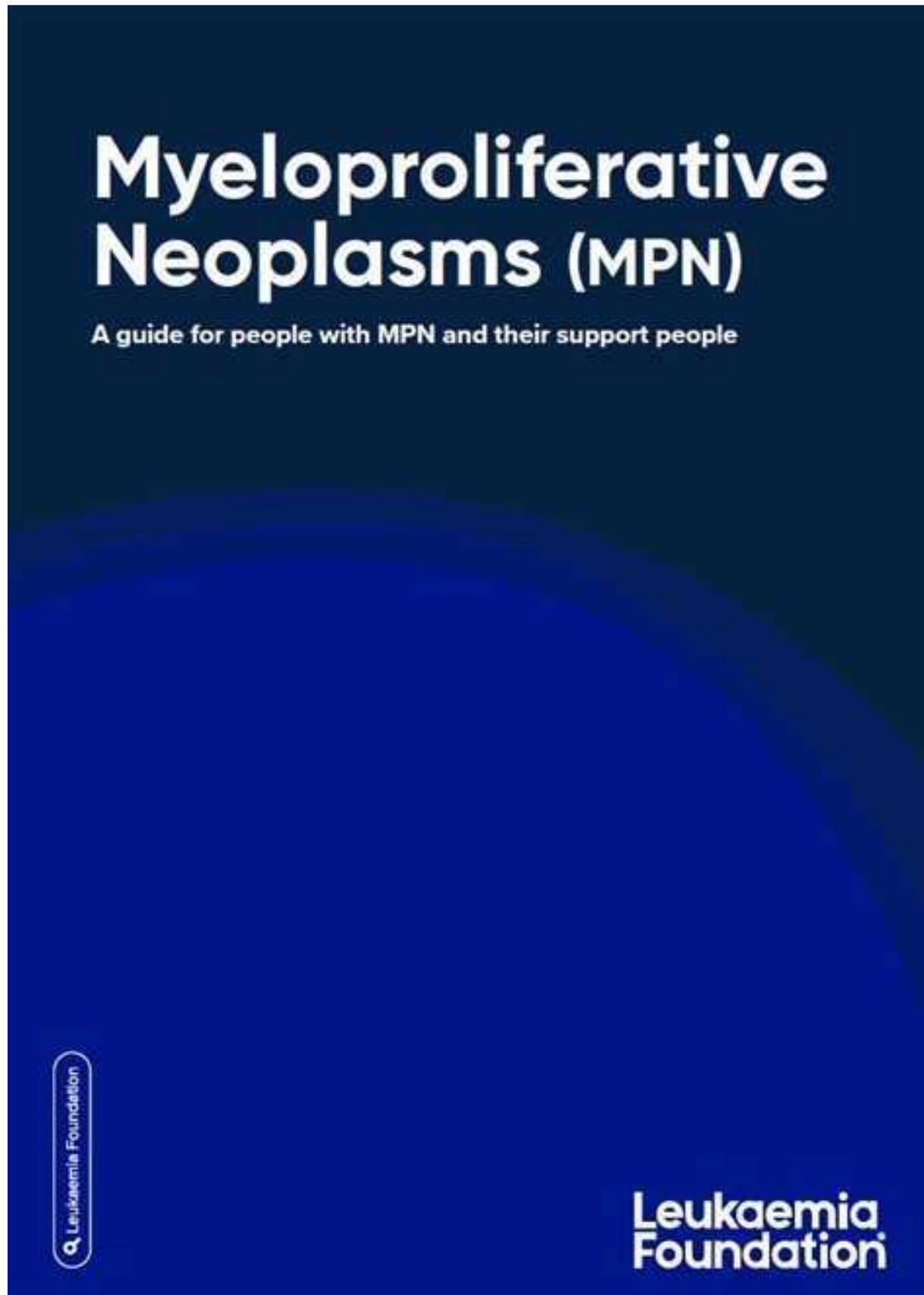


The Leukaemia Foundation has recently produced a webinar entitled "[Exploring real life with blood cancer: The mind and body experience](#)".

This excellent webinar features patient stories as well as the following

presentations:

- 'Living your best life with blood cancer' with Dr Cecily Forsyth (Clinical Haematologist, Central Coast Haematology)
  - 'Psychological effects of blood cancer' with Jane Fletcher (Health Psychologist, Melbourne Psycho-oncology Service)
  - 'Fatigue and physical effects of blood cancer' with Julie Allen (Physiotherapist and lymphoma survivor)
  - Panel Q and A session
-



The Leukaemia Foundation provides a range of information and services to support and inform blood cancer patients. We are very pleased that it has just released a new MPN booklet [Myeloproliferative Neoplasms – a guide for people with MPN and their support people](#) (November 2021).

This is a detailed booklet about MPNs, medically reviewed and updated. You'll find it contains plenty of helpful information about diagnosis, treatment, navigating the health system and much more.

If you would like a hard copy of the booklet, please contact the Leukaemia Foundation on 1800 620 420



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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