

# Blood cancer what is the GP's role?

[leukaemia.org.nz](http://leukaemia.org.nz)  
0800 15 10 15



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# Blood cancers – a snapshot

Every 4 hours a New Zealander is diagnosed with a blood cancer or related condition, that's the equivalent of 2,200 New Zealanders a year.

Blood Cancer Awareness Week from 3 – 7 November is Leukaemia & Blood Cancer New Zealand's annual national awareness week.

- Blood cancers combined (leukaemia, lymphoma and myeloma) are the fifth most common form of cancer in New Zealand
- Blood cancers combined are the 3rd most common cancer killer
- Leukaemia is the most common childhood cancer
- Lymphoma is the most common form of cancer in 15-24 year olds
- The cause of blood cancers is unknown
- Immediate treatment may be necessary and that treatment can go on for months or even years

Blood cancers contribute significantly to the annual cancer burden in New Zealand. Blood cancer is a general term for malignancies of the blood, bone marrow or lymphatic system.

The three main types of blood cancer are leukaemia, lymphoma and myeloma (also known as multiple myeloma).

Leukaemia is the malignancy of cells in the bone marrow. Lymphoma refers to malignant tumours of the lymphatic system and myeloma is the malignancy of plasma cells that produce antibodies.

The different blood cancers have varying prognoses depending on patient factors and the disease sub-type and for many of these disorders it has been shown that early diagnosis can be crucial to achieving good outcomes. Survival rates have increased in recent years with timely, appropriate and modern treatments.

**Leukaemia & Blood Cancer New Zealand offers CME sessions to GPs about blood cancer**

**If you're interested in finding out more please contact our team on 0800 15 10 15**

# Support needs for patients living with and beyond blood cancer

**It is estimated that there are 10,000 people living with and beyond a blood cancer in New Zealand and many of these patients will experience long-term consequences of their diagnosis and/or treatment. These can include both physical and psychological late effects and can present during or immediately after treatment, or many years later.**

A survey conducted in the UK indicated that 94% of people living after cancer experienced at least one adverse effect of their disease or treatment in the first year after treatment<sup>1</sup> with 71% experiencing at least one symptom more than 10 years after treatment<sup>2</sup>.

The longer term management of the consequences of a blood cancer diagnosis and treatment can often fall within the scope of health care professionals in primary care. Most patients living with cancer would go to their GP for symptom management<sup>2</sup>. Therefore GPs and practice nurses should be familiar with the potential of both the physical and psychological consequences of a blood cancer diagnosis and/or treatment.

## Physical consequences

Common treatment modalities for blood cancers include chemotherapy, radiation therapy and stem cell transplants and the physical late effects from these forms of treatment can include:

- Fatigue
- Weight changes
- Fertility issues
- Neuropathic pain
- Heart damage leading to an increased risk of cardiovascular disease
- Lung damage
- Osteoporosis
- Second malignancy
- Chronic pain

Specific late effects can be attributed to different forms of treatment. Haematologists can provide GPs and practice nurses with information about which late effects to monitor for.

<sup>1</sup> Macmillan Cancer Support (2008) Macmillan Study of the Health and Well-being of Cancer Survivors – Follow-up Survey of Awareness of Late Effects and the use of Health Services for ongoing health problems. London.

<sup>2</sup> Macmillan Cancer Support (2009) It's no life. Living with the long-term effects of cancer. London.

## Psychosocial consequences

It has been estimated that up to half of all cancer patients will be diagnosed with psychosocial morbidity<sup>3</sup>, however the psychological needs of people living with and beyond cancer are the most frequently overlooked<sup>4</sup>. Furthermore, 45% of people with cancer say the emotional effects of cancer are the most difficult to cope with, compared to the physical and practical aspects<sup>5</sup>.

The period of time immediately following diagnosis and treatment can be a time of great distress. A quarter of people with cancer feel abandoned<sup>6</sup> either because they have moved from intensive interaction with healthcare professionals and/or because there may be a significant period of time before their next follow-up appointment<sup>5</sup>. GPs and practice nurses can play a role in supporting patients during this time.

The psychosocial concerns of people living with and beyond blood cancers include:

- Anxiety and depression
- Fear of disease reoccurrence
- Survivorship guilt
- Cognitive impairment including memory loss and problems with concentration
- Career instability
- Financial insecurity
- Relationship breakdowns
- Re-assimilation into peer group
- Concerns around sexuality and altered body image

- Lower educational attainment for children and adolescents
- Stigmatisation and discrimination

## Caring for carers

Family, friends and others close to the patient are sometimes described as secondary survivors<sup>6</sup>, acknowledging the integral part they play in supporting patients throughout the experience of living with and beyond cancer. A cancer diagnosis affects the entire family and it can be a demanding, challenging and isolating experience.

Studies have shown a carer's psychological burden can exceed that of a patient<sup>7</sup> and healthcare professionals in primary care are well placed to assess carer's needs and support families through periods of adjustment.

## The role of GPs and Practice Nurses

GPs and Practice Nurses have a role to play in educating patients about long-term effects and supporting them in self-management. By being aware of the possibility of late effects GPs can proactively ask patients about possible treatment-related problems and psychosocial concerns, as part of any regular review<sup>8</sup>.

Ongoing communication between primary care providers and haematology specialists is essential. Haematologists need to provide clear information to patients and GPs about possible long-term consequences.

## The role of the patient

Patients should engage in self-management strategies such as monitoring for late effects and reporting any concerns they may have.

It is important that people living with and beyond blood cancers mitigate risks through safe sun exposure, healthy diet, regular exercise, smoking cessation and moderate alcohol intake.

3 McQuellon RP, Danhauer SC. (2007) Psychosocial Rehabilitation in cancer care. In: Ganz, PA (ed). Cancer Survivorship Today and Tomorrow. New York, Springer.

4 Armes, J., Crowe, M., Colbourne, L et al. (2009). Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. J Clin Oncol 9(3): 6172-9.

5 Macmillan Cancer Support (2006). Worried Sick: the emotional impact of cancer. London.

6 Rowland JH. (2007) Survivorship research: past present and future. In: Ganz PA (ed). Cancer Survivorship Today and Tomorrow. New York, Springer.

7 Hodgkinson K, Butow, P., Hobbs, K et al. (2007) After cancer: the unmet supportive needs of survivors and their partners. J Psychosoc Oncol. 25(4): 89-104.

8 Burton, C (2010) The effects of surviving cancer. GP: General Practitioner. Retrieved from <http://www.gponline.com/effects-surviving-cancer/cancer/treatment/article/1001865>

# The role of Leukaemia & Blood Cancer New Zealand (LBC)

Most psychosocial morbidities can be managed without specialist psychological support<sup>4</sup>. LBC is the only not-for-profit organisation in New Zealand dedicated solely to supporting patients and family members living with or beyond a blood cancer or related condition. LBC Support Service Coordinators are experienced haematology and oncology health professionals and welcome all referrals.

## We offer:

- Personalised emotional support through regular phone calls, face-to-face visits, contact in the hospital or via email
- A variety of support and education groups

- Educational events for patients and their families, including our annual patient forum, host guest speakers and run mindfulness stress based reduction programmes

## Other LBC Services

**Research** – we support and fund research into blood cancers and related conditions and provide educational grants to health professionals.

**Advocacy** – we represent the needs of patients and families to the government, related agencies and other relevant organisations. We also act on behalf of patients about issues arising from their diagnosis.

**Awareness** – we work to increase public knowledge of blood cancers and related conditions.

# Resources

## For the healthcare professional, patient and community

Leukaemia & Blood Cancer New Zealand (LBC) produce a range of educational materials.

### Booklets

We have a wide range of booklets for patients and their family/whānau and friends, which are reviewed by haematologists. These include information about blood cancers and related conditions, their treatment and support available.

Our “Blood Cancer and Conditions” booklet is available in 9 languages: Māori, Samoan, Cook Island Māori, Niuean, Tongan, Chinese (Simplified and Traditional), Korean and Hindi.



### DVDs

LBC have produced a wide range of DVDs providing a comprehensive overview of blood cancer with focus on bone marrow biology, disease specific information and management strategies.

### Children's books

We currently have four picture books which have been written specially for children who have been diagnosed with a blood cancer. These are also useful when a family member has been diagnosed. They describe the processes of diagnosis and treatment, and are a helpful tool to explain these concepts to children.



### Publications

We produce four magazines: LifeBlood, Leukaemia Today, Lymphoma Today and Myeloma Today which feature patient stories, coping strategies and important information for those affected by blood cancer.

### Resource Library

We have a large selection of books, CDs and DVDs available for loan. LBC also publish a list of recommended websites should patients or professionals want to seek information online.

### Diagnostic information

“Diagnosing Lymphoma” is a diagnostic tool designed to help guide the practitioner during the work up of a lymphoma patient. The tool includes the symptoms, investigations, diagnosis and referrals that a GP may encounter with this patient group.

Alongside these recommendations, an article titled “Early Diagnosis and Referral of Lymphoma is Critical” was published. This outlines the significance of Lymphoma in New Zealand and the role GPs play in improving outcomes.



### Leaflets

We have produced a series of Understanding Blood Cancer A4 tear away leaflets, for leukaemia, lymphoma and myeloma.

Each leaflet gives a brief overview on the condition, signs & symptoms, diagnosis and treatment options for the specific disease. They are also available as large posters for display.



### Where can you get these resources?

All resources are available at no cost. Please visit [leukaemia.org.nz](http://leukaemia.org.nz) or contact our Support Services team on **0800 15 10 15**.



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