Blood cancer patients are being denied access to expert care and support.

Receiving a blood cancer diagnosis is an extremely worrying and disorienting time for patients. Access to a Clinical Nurse Specialist (CNS) has been identified by patients as the single most important thing that improves their experience during this traumatic time – yet 5,000 blood cancer patients each year are still being denied access.
A Clinical Nurse Specialist (CNS) can provide the personalised support that a patient needs after being diagnosed with a blood cancer.

Many patients have told us of their frustrations at seeing multiple healthcare professionals, and having to explain their care history each time a new professional is introduced.

"I think it was the care that I received on that ward from my specialist nurse that got me through it."

Linda, Acute myeloid leukaemia (AML) patient

A CNS can provide patients with emotional and psychological support, and can act as the single point of contact to help patients navigate their way through an often complicated care pathway. This can involve recommending additional support services that may be of use, such as a psychiatrist, social worker or counsellor, and helping the patient access them.

For all cancer patients, the value of having a CNS cannot be overstated. Having access to a named CNS was identified as the number one indicator of a positive patient experience in the 2014 National Cancer Patients’ Experience Survey.

"A CNS is even more valuable for blood cancer patients. Patients are often confused at the point of a blood cancer diagnosis. A complicated disease area, many patients will not have heard of their blood cancer – they won’t know anything about the disease or the treatment options, or know anyone who has had it.

In addition, the needs of blood cancer patients differ from those of solid tumour cancer patients. These factors often lead to a feeling of isolation in comparison to a diagnosis with one of the more well-known cancers – and access to a CNS can go a long way to addressing these issues for blood cancer patients."

Kirsty Crozier, Senior Advanced Nurse Practitioner for myeloid disorders

"It was around six years after my chronic leukaemia diagnosis that I was first given the contact details for my CNS. The difference it made knowing she was there during difficult times cannot be put into words. Getting a smile and a hello from her in clinic, and knowing she cares, is a truly wonderful thing."

Katie, Chronic myeloid leukaemia (CML) patient

What is blood cancer?

Blood cancer is a complicated disease area of 137 different cancers. The most common groups within blood cancers are types of leukaemia, lymphoma and myeloma. 38,000 people are diagnosed with a blood cancer every year, the fifth highest amongst all cancers.
Clinical Nurse Specialist access for blood cancer patients

Patient Need – our comprehensive research into the needs of blood cancer patients – gathered the views of nearly 2,000 patients, and was the largest study of its kind.¹

Blood cancer patients told us that access to a CNS can be inconsistent. In some areas of the country, patients have access to a highly specialised CNS, with each blood cancer having its own designated nurse. In other areas however, a single CNS will have responsibility for supporting all blood cancer patients. But most seriously, patients in some parts of the country have no access to a CNS at all.

The National Cancer Patient Experience Survey shows that fewer blood cancer patients (87%) have access to a CNS than patients with other common cancers. Across the 38,000 new diagnoses a year, this equates to 4,940 patients not accessing a CNS. Further research commissioned by Bloodwise shows that this figure is even lower for patients diagnosed with two common forms of leukaemia, chronic myeloid leukaemia (CML) and chronic lymphocytic leukaemia (CLL). Finally, access for patients with rarer blood cancers is even worse, with only 77% of patients accessing a CNS.

A CNS can offer invaluable support to a patient at diagnosis and throughout their patient journey. Our Patient Need research clearly demonstrates that currently too many blood cancer patients – one in six – don’t have their needs met at the point of diagnosis. The challenge of supporting patients living with blood cancer is expected to grow in the years ahead – the development of innovative new treatments means blood cancers are increasingly becoming long term conditions that will be managed for several years, rather than cured. This means that access to a CNS will become more important, as patients will need support for a much longer period of time.

² NCPES report for blood cancer type, 2014
³ Patient Need report, 2015

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Access to a CNS by cancer type ²

- Breast and gynaecological: 93%
- Lung: 92%
- Colorectal, lower gastro and upper gastro: 91%
- Blood cancer average: 87%
- CML and CLL: 81%
- Other rarer blood cancers: 77%

Extent to which blood cancer patient needs were met at diagnosis ³

- Met very well: 47%
- Met well: 22%
- Neither: 13%
- Not met well: 9%
- Not met at all well: 5%
- No answer: 5%
Our call

The Independent Cancer Taskforce[^4] rightly identified the key role a CNS plays in supporting a patient throughout their diagnosis and treatment, and the need for the cancer nursing workforce to keep pace with the growing number of people with cancer.

It’s essential that the Implementation of the Cancer Strategy[^5] prioritises increasing the number of training positions, and ensures equity of patient access to a CNS or other key worker from diagnosis onwards.

We’re calling on the Government and the NHS to:

**ONE**

Improve access so that all blood cancer patients have a named Clinical Nurse Specialist.

**TWO**

Work with Royal Colleges and the NHS to increase understanding of how the needs of blood cancer patients are different from solid tumour cancer patients, and how care packages need to reflect this.

**THREE**

Work with Bloodwise and other charities in the blood cancer sector to increase patient awareness of the specialist nursing provision available to them.

**FOUR**

Undertake research to assess the true picture of Clinical Nurse Specialist provision.

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[^5]: https://www.england.nhs.uk/2015/01/beat-cancer/

**Find out more**

To find out more about Bloodwise and what we’re doing to beat blood cancer, visit bloodwise.org.uk or email policy@bloodwise.org.uk

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Diana Jupp, Director of Patient Experience, Bloodwise