

CLLSA

All-Party Parliamentary Group on Blood Cancer report

An Important Day for people with CLL



We're delighted to announce that the inaugural report of the All Party Parliamentary Group (APPG) on Blood Cancer is being launched at Westminster today. **The report calls to the Government and NHS to ensure that blood cancers and the needs of blood cancer patients are properly addressed.** CLLSA has been actively involved in supporting this APPG and will be attending the launch this afternoon.

The Need for Psychological Support

Particularly pertinent to many CLLSA members will be the priority recommendation that tailored psychological support must be made available to those patients on "watch and wait".

The report recognised that some patients with chronic blood cancers, such as CLL, will never be cured and the regime of "watch and wait" can lead to psychological distress.

The report recommends that NHS England should continue to work with charities, patients and healthcare professionals to ensure that emotional and psychological support is available to patients and their families from the point of diagnosis.



Clinical Nurse Specialists

Access to a named Clinical Nurse Specialist has been identified by patients as the single most important thing that improves their experience of care.

However, one in ten blood cancer patients still does not have a named Clinical Nurse Specialist. This negatively impacts their experience of blood cancer care. Work is being undertaken by NHS England to see how this level of support could be replicated by an alternative model of care and this is welcome.

Patients and their families sometimes feel let down by a lack of specific policy attention and action. **Much more needs to be done to ensure that the needs of blood cancer patients, which can often be different from other cancers, are met and those affected can feel confident that their care will be comprehensive, effective and tailored to them.**

CLLSA

The guiding principles from the APPG on Blood Cancer report are:

1. Develop and support initiatives to raise awareness of blood cancer and improve early diagnosis
2. Blood cancer patients, and their experiences, should be at the heart of cancer policy making
3. Living with and beyond cancer policy initiatives should recognise the unique needs of people with blood cancer
4. Increase funding for research in blood cancer with a focus on improving access to treatment for patients
5. Ensure NHS commissioning and other processes work for blood cancer patients now.

Priority recommendations from the APPG on Blood Cancer report includes Early diagnosis: Delays in blood cancer diagnosis can have a major impact on a patient's quality of life and overall outcome and earlier diagnosis would make a difference for many, but not all, blood cancers.

In order to change this, recommendations for early diagnosis in the Cancer Strategy should be reviewed to ensure that all people with blood cancer are benefitting from early and accurate diagnosis. **GPs should undertake a simple blood test for people displaying one or more blood cancer symptoms.**

The Cancer Strategy says that all cancer patients will have had access to the Recovery Package by 2020. This 'Package' helps patients once their treatment has ended so they can return to their normal lives.

NHS England should consider how all blood cancer patients can benefit from after-care support including ensuring the Recovery Package takes account of the unique characteristics of blood cancer.

NHS Commissioning

Cancer Alliances should reduce fragmentation between different stages of care for blood cancer patients by bridging recognised gaps between oncology and haematology departments, for example, and between primary and secondary care.

Research

Unlike treatment of solid tumour cancers, blood cancers are often not treatable using surgery or radiotherapy. This means that blood cancer is more dependent on the development of new drugs, and being able to access them, in order to continue improving patient outcomes.



Ongoing, stable Government investment in blood cancer research, including in clinical trials infrastructure, is required to capitalise on the UK's position as a leader in blood cancer research. This will deliver benefits for patients and help Government reach ambitions outlined in the UK Life Sciences Industrial Strategy.