LYMPHOMA
COALITION
Worldwide network
of lymphoma groups

INTERNATIONAL LYMPHOMA PATIENT CHARTER

RATIFIED BY LYMPHOMA COALITION MEMBERS
MARCH 2006

> “ Vision Statement
>
> This international charter was created to ensure that the more than one million people living with lymphoma worldwide[1] have access to the best available care, information and support. The number of lymphoma cases is increasing rapidly[2] and there is a critical need for patients to be better informed regarding their disease[3]. Much can be done to improve the current situation and this is the responsibility of society as a whole, including healthcare professionals, patient groups/advocates, governments, insurers, payors/funders, clinicians, researchers and industry. To ensure that lymphoma patients receive the best treatment available, it is vital that the rights outlined in this charter are adopted globally. ”

All patients are entitled to the rights outlined in this charter regardless of age, gender, marital status, ethnicity, religion, sexual orientation, educational or economic background. This charter supports every stage of the patient journey through diagnosis, treatment, follow-up care and monitoring.

Diagnosis

All lymphoma patients are entitled to timely investigation and an accurate diagnosis by a qualified medical expert with a specialty in blood diseases such as haematopathology. It is critical that specialised imaging and scanning procedures are utilised to determine the extent of disease progression for appropriate treatment planning. All patients are entitled to a second opinion and referral to a haematopathologist, who can review their case and diagnostic material.

Treatment

Patients are entitled to have access to optimal treatment, based on an accurate diagnosis, stage of the disease and current evidence-based medicine. Patients have a right to know about all available treatment options and should be informed of relevant clinical trials. Financial status should neither be a barrier nor a determining factor in informing patients about treatment options, as all patients have a right to optimal treatment and it is in their best interest to know about the latest advances in the field. Patients are entitled to be an active participant in the treatment decision-making process.

Follow-up

Because lymphoma can recur, patients are entitled to regular follow-up care and close monitoring. Lymphoma patients have a right to receive a continuum of care provided by a dedicated team of healthcare specialists, counsellors, nurses, nutritionists and palliative care specialists, if required.

Long-term follow-up and ongoing interaction between all of these parties and the patient is crucial to determine the best course of action.

Information

Patients are entitled to be provided with all necessary information regarding their diagnosis, treatment and overall disease management and should be encouraged to become active participants in the treatment decision process.

This information should include:

1) nature of the disease
2) treatment options
3) risks and side effects of treatment
4) clinical trial opportunities
5) patient support tools and advocacy groups

Support

Patients are entitled to be informed of all available support systems, including patient support tools and advocacy groups. Patients are entitled to have a "voice" in their own disease management. Patient support tools and advocacy groups can play a key role in a patient's recovery process and can help them access a host of resources, from psychological support to family counselling. Through advocacy groups, patients can also become involved in health policy discussions that can impact disease management for all lymphoma patients. Having the right support network is invaluable for patients at all stages of their illness.

References:

1. GLOBOCAN 2002: Descriptive Epidemiology Group of the International Agency for Research on Cancer (IARC)
2. http://www.lymphoma.org/site/pp.asp?c=bfIKIVMIG&b=38240
3. NOP September 2005 data on file