

*A phase II study VEPEMB
In patients with Hodgkin's Lymphoma
Aged 60 years and older*

QUESTIONNAIRE

QUALITY OF LIFE

Dear Patient

We would like to ask for your co-operation and help. Great improvements in the treatment of your illness have been achieved over the past twenty years so that most patients can be cured today. However, over recent years more and more attention is being given to finding new treatments that have fewer side-effects.

Questions were raised about how the *Quality of Life* of patients is affected by the disease and the treatment and which measures they use to help overcome these difficulties. Furthermore, more information is needed about how patients cope with their illness and the effects of treatment, in order to make treatment more successful. It is of course essential that patients are able to cope with the disease and side effects of treatment and are able to return to normal life as soon as possible. Until now very little was known about general and specific physical, psychological and emotional experiences of patients who had radiotherapy and/or chemotherapy for Hodgkin's disease.

In trying to make a significant step forward regarding these points, a questionnaire has been designed to obtain the most relevant information from the patient's own point of view. The intention is to collect this information repeatedly during at least five years of follow-up. This information can be of great help to improve understanding of points in time when particular problems arise. In future this information could be used to develop more precisely measures of help and support and to contribute to further development of the medical treatment itself so that as few as possible negative effects occur.

Your help in participating in this investigation will, therefore, particularly influence the treatment of future patients suffering from Hodgkin's disease but also might be of help for yourself when speaking with your physician about your own situation and possible problems.

We would, therefore, like to ask you to fill in this questionnaire at the follow-up visits. Should, by mistake, the questionnaire not be handed out (or sent) to you, please help by reminding your physician or nurse about it.

For your own information, please note that the problems and side-effects which are mentioned in the questionnaire might bother a number of patients but are by no means likely or expected to occur in all patients. All the information you provide will of course remain confidential and for scientific analysis the forms will be used anonymously only.

Thank you very much for your help and co-operation in this important investigation.

Please answer all of the questions yourself, by circling the number that best applies to you. There are no 'right' or 'wrong' answers.

Please fill in your initials: _____ Female

Your birth date (Day, Month, Year) _____ Male

Today's date (Day, Month, Year) _____

Currently employed Yes No

Profession / work _____

		Not At All	A Little	Quite A bit	Very Much
1	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2	Do you have any trouble taking a <u>long</u> walk?	1	2	3	4
3	Do you have any trouble taking a <u>short</u> walk outside of the house?	1	2	3	4
4	Do you need to stay in a bed or in a chair during the day?	1	2	3	4
5	Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4
	DURING THE PAST WEEK	Not At All	A Little	Quite A bit	Very Much
6	Were you limited in doing either your work or other daily activities?	1	2	3	4
7	Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8	Were you short of breath?	1	2	3	4
9	Have you had pain?	1	2	3	4
10	Did you need to rest?	1	2	3	4
11	Have you had trouble sleeping?	1	2	3	4
12	Have you felt weak?	1	2	3	4
13	Have you lacked appetite?	1	2	3	4
14	Have you felt nauseated?	1	2	3	4
15	Have you vomited?	1	2	3	4

		Not At All	A Little	Quite A bit	Very Much
16	Have you been constipated?	1	2	3	4
17	Have you had diarrhoea?	1	2	3	4
18	Were you tired?	1	2	3	4
19	Did pain interfere with your daily activities?	1	2	3	4
20	Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21	Did you feel tense?	1	2	3	4
22	Did you worry?	1	2	3	4
23	Did you feel irritable?	1	2	3	4
24	Did you feel depressed?	1	2	3	4
25	Have you had difficulty remembering things?	1	2	3	4
26	Has your physical condition or medical treatment interfered with your <u>family</u> life?	1	2	3	4
27	Has your physical condition or medical treatment interfered with your <u>social</u> activities?	1	2	3	4
28	Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4
29	Have you had a dry mouth?	1	2	3	4
30	Have you had tingling (“pins and needles”) in your hands or feet?	1	2	3	4
31	Have you had infections? (Flu, chest infection, skin infection etc)	1	2	3	4
32	Has your interest in sex decreased?	1	2	3	4
33	Has your sexual activity decreased?	1	2	3	4
34	Has your pleasure or satisfaction from sex decreased?	1	2	3	4
35	Were you worried that you may not be able to have children anymore?	1	2	3	4

For the following questions, please circle the number between 1 and 5 that best applies to how you have been feeling lately.

		Yes, that is true				No that is not true
36	I feel fit.	1	2	3	4	5
37	Physically, I feel only able to do a little.	1	2	3	4	5
38	I feel very active.	1	2	3	4	5
39	I feel like doing all sorts of nice things.	1	2	3	4	5
40	I feel tired.	1	2	3	4	5
41	I think I do a lot in a day.	1	2	3	4	5
42	When I am doing something, I can keep my thoughts on it.	1	2	3	4	5
43	Physically, I can take on a lot.	1	2	3	4	5
44	I dread having to do things.	1	2	3	4	5
45	I think I do very little in a day.	1	2	3	4	5
46	I can concentrate well.	1	2	3	4	5
47	I am rested.	1	2	3	4	5
48	It takes a lot of effort to concentrate on things.	1	2	3	4	5
49	Physically, I feel I am in a bad condition.	1	2	3	4	5
50	I have a lot of plans.	1	2	3	4	5
51	I tire easily.	1	2	3	4	5
52	I get little done.	1	2	3	4	5
53	I don't feel like doing anything.	1	2	3	4	5
54	My thoughts easily wander.	1	2	3	4	5
55	Physically, I feel I am in an excellent condition.	1	2	3	4	5

For the following questions, please circle the number between 1 and 7 that best applies to you.

		Very poor						Excellent
56	How would you rate your overall <i>physical condition</i> during the past week?	1	2	3	4	5	6	7
57	How would you rate your overall <i>emotional condition</i> during the past week?	1	2	3	4	5	6	7
58	How would you rate your overall <i>health</i> during the past week?	1	2	3	4	5	6	7
59	How would you rate your overall <i>quality of life</i> during the past week?	1	2	3	4	5	6	7

The following questions refer to the time period from diagnosis and start of treatment until today.

		Not At all						Very Much
60	How much did the disease treatment affect your self-confidence?	1	2	3	4	5	6	7
61	How much of an emotional burden was the disease and treatment for you?	1	2	3	4	5	6	7
62	Has your relationship with your partner changed?	1	2	3	4	5	6	7
In which respect?								
63	How much did the disease and treatment affect your sex life?	1	2	3	4	5	6	7
In which respect?								
64	In general, how difficult was the disease and treatment for you?	1	2	3	4	5	6	7
In which respect?								

		Yes, Definitely						Under no Circumstances
65	From your own experience, would you recommend this form of treatment to a close friend or relative with the same disease?	1	2	3	4	5	6	7
66	Looking back, would you again agree to have the treatment you received?	1	2	3	4	5	6	7
67	In which regard would you decide differently today?	(regarding?)						
68	What has been the most difficult consequence of your treatment?							
69	Was something important not mentioned?							