

Living with Hairy Cell Leukaemia - A Quick Guide



Contents

This is a brief summary of **Living with hairy cell leukaemia**. You will find more detailed information on the website.

In this information there are sections on

- Coping with hairy cell leukaemia
- Questions for your doctor
- Leukaemia organisations

Coping with hairy cell leukaemia

It can be very difficult to cope with a diagnosis of HCL, both practically and emotionally. You are likely to be feeling upset and confused.

It is important that you have enough information to make decisions about your treatment, if that is what you want to do. At every stage, you and your relatives should have clear and complete information from your doctors and nurses about all aspects of your leukaemia and treatment.

Remember that HCL can be so slow to develop that for many people it can be some time before they need treatment. And the treatment available now means that it is so well controlled that it may not be the illness that ends their life.

Adjusting to any new situation in life takes a while. Give yourself that time. There is no right or wrong way to approach this. But it will help if you have someone to share your feelings with.

As well as the support that is available to you at the hospital, there are leukaemia and cancer support groups around the country. Your cancer nurse might be able to tell you about local support groups. Or you may want to contact one of the leukaemia organisations.

The coping with cancer section of the website contains lots of information about coping practically and emotionally that you may find helpful.

Questions for your doctor about living with hairy cell leukaemia

- How will my treatment affect me?
- Will I ever get back to normal?
- Will I have treatment side effects that affect my daily life?
- Will I be able to go back to work?
- Is there anything I should or shouldn't eat?
- Where can I get help with claiming benefits and grants?
- What practical help is available?



- Why did this happen to me?
- Are my children at risk of getting cancer?
- Where can I get help dealing with my feelings?
- Can you refer me for counselling?
- Do I have to pay for counselling?
- Could you refer me to a Macmillan nurse?

Leukaemia organisations

Cancer Research UK
 Main website: www.cancerresearchuk.org
 Patient information website:
<http://cancerhelp.cancerresearchuk.org>
 Cancer Information Nurses phone: 0808 800 4040

Leukaemia and Lymphoma Research
 Tel: 020 7405 0101
 email: info@beatbloodcancers.org
 Website: www.beatbloodcancers.org

Leukaemia CARE
 24 hour care line: 08088 010 444
 Tel: 01905 755977
 Website: www.leukaemiacare.org.uk
 email: care@leukaemiacare.org.uk

CLL Support Association
 Phone: 0800 977 4396 or 020 7644 3052
 Website: www.clisupport.org.uk
 Email: info@clisupport.org.uk

More information

For more information about hairy cell leukaemia, visit our website <http://cancerhelp.cancerresearchuk.org>

You will find a wide range of detailed, up to date information for people affected by cancer, including a clinical trials database that you can search for trials in the UK. You can view or print the information in a larger size if you need to.

For answers to your questions about cancer call our Cancer Information Nurses on **0808 800 4040**
 9am till 5pm Monday to Friday

Adapted from Cancer Research UK's Patient Information Website CancerHelp UK in April 2012. CancerHelp UK is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through CancerHelp UK and our nurse team is not a substitute for professional care and should not be used for diagnosing or treating a health problem or disease. If you have, or suspect you may have, a health problem you should consult your doctor. © Cancer Research UK 2012. Cancer Research UK is a registered charity in England and Wales (1089464) and in Scotland (SC041666)