



Ask about your lymphoma medicines

Questions to help you feel informed about
your drug treatments



Lymphoma
association

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This booklet is to help you understand your treatment.

The decisions about treatment will be yours. Your medical team will want you to be involved when choosing the best treatment. They should make sure that you understand what is going to happen before treatment begins. Asking questions is an important part of understanding.

Sometimes it is hard to know what to ask your doctors and nurses. This booklet suggests questions that you might like to ask. You can also use this booklet to write down questions of your own, or to make notes about the answers to your questions.

Lymphoma can be treated in different ways. There are different kinds of lymphoma, and they each have a particular kind of treatment. Some people with lymphoma will need no treatment at all to start with.

This booklet is about treatment with chemotherapy and other drugs.

If you need more information you can contact the Lymphoma Association helpline on 0808 808 5555. Calls to this number are free and confidential. The helpline is open 9am – 6pm, Monday to Friday.

Choosing treatment

You will have lots of tests at the time of your diagnosis. These tests are to find out about your lymphoma. The information will help to plan what treatment will be best for you.

These are questions that you might like to ask at this stage.

- What kind of lymphoma do I have?
- What is the best way to treat my lymphoma?
- Are there other treatments available?
- Are there advantages or disadvantages to the other treatments?
- Will I have chemotherapy?
- Will I have other drugs with my chemotherapy?
- Will I have antibody therapy?
- Will I need this treatment straight away?
- Is the treatment intended to cure my lymphoma?
- How long will the treatment take to work?
- How will you know if the treatment is working?
- Do I have to have this treatment?
- What will happen if I choose not to have this treatment?
- Can I get a second opinion about this choice of treatment?
- Has my case been discussed with other specialists?
- Can I change my mind after treatment has started?
- Can I have the same treatment again if I need to?

- What are the side effects of the individual treatments? Are the benefits of treatment worth the side effects? Are there other treatments that have fewer side effects?
- What are the long term side effects of the individual treatments? Do other treatments have fewer long term side effects?
- Will treatment affect my fertility? Can I do anything about this before treatment begins?
- Might I be eligible for a clinical trial?

There are some terms you might like to ask about:

- What is the difference between remission and cure?
- What is meant by remission?
- How long does remission last?
- What do you mean by 'stage'?

Remember that some questions will be difficult for anyone to answer. In many cases, there will be very few treatments to choose from. Tell your doctor about other medicines you are taking. You might like to take them to hospital with you.

Tell your doctor about any other medical conditions that you have. Ask about where to go for more information about your lymphoma and its treatment.

Taking treatment

These questions will help you to know what to expect of the treatment you have chosen.

Ask about the practicalities:

- How long will the course of treatment take?
- How often will I have to come to hospital?
- How long does it take each visit?
- Where do I have to go?
- Can I have treatment nearer to home?
- Will it cost me anything? If so, can I get help with these costs?
- Can I get help with transport? Can I get help with transport costs?

Ask about the individual drugs:

- What are the names of the drugs I am having?
- Can you tell me which ones are chemotherapy?
Which ones are steroids? Which ones are antibody therapy?
- Which drugs are to help with side effects?
- How do the drugs work? Do some work in different ways to others?
- When will I know they are working? How will you know they are working?

Ask about side effects:

- What are the side effects of the individual drugs?
- When will these side effects happen?
- When will side effects be at their worst?
- How long will they last?

- What can be done to help with side effects?
- Are there any symptoms I need to look out for?
- How will I know if I am getting an infection?
- What should I do if I think I'm getting an infection?
- Where do I go if I need help?
- What happens if I need help out of hours?
- What do I do in an emergency?
- What if the side effects are too bad? Can I change my mind?
- Can treatment be delayed? What happens if treatment is delayed?

Ask about taking care of yourself. Ask about other aspects of life:

- What can I do to help myself?
- Do complementary therapies make a difference?
- Will I have trouble eating? What can I do to help with this?
- Can I exercise?
- Can I have sex?
- What about contraception?
- Can I drink alcohol?
- Should I keep taking my other medicines?
- Can I still go on holiday?
- Can I still go to work
- Can I still go to school or university?

Ask about what happens after treatment has finished:

- What happens next?
- How do you know if I am in remission?
- Will I need more tests?
- Is there anything that will help me to stay in remission?
- What if my treatment hasn't worked?

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Ask About Medicines is the independent campaign to increase people's involvement in decisions about their use of medicines.
www.askaboutmedicines.org

Other useful organisations

Cancerbackup - Freephone helpline 0808 800 1234 www.cancerbackup.org.uk
Macmillan Cancer Support - Macmillan CancerLine 0808 808 2020 www.macmillan.org.uk

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