

## The emotional impact of lymphoma

This article is for anyone who:

- has recently been diagnosed with lymphoma
- is receiving treatment for lymphoma
- is not on treatment but is worried about their lymphoma getting worse or coming back
- is trying to support a family member or friend who is going through these things.

The article will discuss the problems you can have in adjusting to the diagnosis, the treatment and follow-up, focusing on:

- the importance of getting the right information and the right amount of information
- common feelings people can have
- ideas to help you cope and what to do if you are having difficulties.

### Just been diagnosed?

Being diagnosed with lymphoma could be the most difficult experience you will ever have faced. When you are told that you have lymphoma you can experience a wide range of emotions. People often describe feeling shocked, frightened, devastated or hopeless after their diagnosis.

These emotions can be very strong. This is often because when people hear the word 'lymphoma' or 'cancer' they automatically think of the possibility of dying. This could be because of the way cancer is talked about in the news or on TV, or because of past experiences with relatives or friends. However, the chances of you surviving are better now than they have ever been and many lymphomas are now cured. Although this will not be possible for everyone, medical treatments can control the lymphoma for many years.

### Understanding what is happening

When you are first told, you might have been so shocked or anxious that you were not able to pay attention to anything the doctor was saying. All the information you suddenly need to take in after your diagnosis can seem overwhelming – information about the lymphoma itself, information about the tests you will need, treatment, side effects, work, benefits, and many other things. You might feel that you just have too many choices and decisions to make and you can then begin to feel even more anxious and unable to control the situation.

You may also find yourself getting too much information, which you don't feel ready for. For example, websites can be very useful but can also provide far more information than you need or want. This can be a problem if it makes you feel more worried. Difficulties can also arise if you feel you have been given conflicting information.

Getting the right information is a difficult balance. You are the only person who knows when and how much new information you are ready for.

## **Where to get information and how to ask**

Your hospital doctors and nurses are the main people to turn to for information about your illness and treatment. If you want to know more, or if you haven't understood what you have been told, then ask them more questions. They will be happy to help you with your queries. You might find that it helps to take someone with you to hospital appointments. They can help you remember what the doctor has said. Writing down your questions before appointments and taking a note of the answers can also be helpful.

Your GP is unlikely to have a lot of experience of lymphoma but they will be kept informed of your test results, treatment plan and progress, so will know a good deal about your situation. They would be able to seek information from the hospital on your behalf and they, or another member of the practice would be able to advise you how to access various forms of support.

Bookshops, your local library and the internet are also possible sources of useful information. There is a huge amount of information available on the internet and much of this is accurate and helpful. You have to be aware, however, that not all the information available online is good-quality information. Make sure that the websites you are using are well respected.

If you read something in a book or on a website that worries you, ask your medical team about it. People often say that they are worrying about things they have read, and then find that these things don't apply to them but to people with other kinds of lymphoma.

We will make a few suggestions of useful websites and books at the end of the article.

We also produce a wide range of carefully researched booklets and information sheets about lymphoma which our medical advisers have either written or reviewed. These are available online at [www.lymphomas.org.uk](http://www.lymphomas.org.uk) or you can ring our freephone helpline on 0808 808 5555 and ask for them to be sent to you free of charge.

## **How do you feel?**

Although for some people there will be a degree of relief to have a diagnosis after weeks or even months of feeling unwell, it is very likely that you will experience a range of negative feelings when you are told that you have lymphoma. For example, since your diagnosis, have you felt:

- worried, fearful or panicked?
- alone?
- sad or hopeless?
- angry or frustrated?
- like blocking everything out?
- out of control?
- numb?
- guilty?

These are all normal emotions that people can feel when they find out they have lymphoma or are receiving treatment. These feelings don't come in any particular order, and they can come and go. There is no right way of feeling and no wrong way.

## What makes you feel this way?

There are a lot of things that can affect how you feel. As we suggested earlier, not understanding what is happening to you or how to make decisions on your treatment can make you feel as if you aren't in control. It is also natural to feel uncertain about what the future holds, how you will feel when you have the treatment, whether the treatment will work, whether you might die. Many people worry about their family and other loved ones, about how they will manage emotionally, practically and financially.

You might also feel a lot of pressure to stay positive and to 'fight' your illness. This becomes a way of coping for some people and it works for them. It is important, though, to know that everyone copes in their own way and you don't have to be positive all the time. There is no right way of coping and no wrong way of coping, there is just your way. Feeling down or worried is a normal reaction and does not mean that you are in any way weak or failing to cope. And having these normal feelings of anxiety will not affect your lymphoma or harm your recovery.

## Facing months of treatment?

Lots of things change when you are diagnosed with lymphoma and embark on treatment. Some of these changes are predictable, but some are less obvious and can be difficult to adjust to. Common changes that people experience are:

- **Changing routines** – if you are having spells in hospital or times when you are feeling unwell at home, your normal routines will change during your treatment. You might have to stay off work or cancel family or social arrangements. The fatigue that chemotherapy or radiotherapy can cause as a side effect can make you feel extremely tired and sluggish and make it hard to stay active. This tiredness can last for a considerable time after the treatment finishes.
- **Changes to your body** – you might experience temporary problems such as hair loss, weight loss or weight gain with chemotherapy drugs; or you might have longer-term changes to cope with, such as reduced physical strength and fertility difficulties. These changes can be difficult to adjust to and can affect your self-confidence.
- **Changes in your finances** – especially if you have to stop work as a result of your lymphoma. This can lead to a lot of anxiety about money and how you and your family will manage. Remember that financial advisers are available to talk to you about these problems, for example through Macmillan's benefits adviser services (see contact details at the end of this article).
- **Changes in relationships** with your family and friends are not always what you expect to happen. You might find that some friends often ask you about how you are, sometimes when you would rather not talk about it. On the other hand, other people might avoid mentioning your illness at all, which can be quite hurtful. Sexual intimacy can also suffer after being diagnosed with lymphoma and particularly during treatment. If this becomes a longer-term problem that is worrying you or your partner, then information and advice should be available from your medical team.
- **Changing roles** – your role in the family might change as a result of your illness or treatment. For example, you might not be able to look after young children, a partner or an elderly parent

while you are going through treatment. You may have to ask others to help, perhaps something you don't normally like doing. This can be difficult but it is often better in the long run to ask other people to help. They might be pleased and relieved to be able to do something practical for you.

Many of these changes are very hard to adjust to, yet people can experience positive changes following their diagnosis – some people feel great relief to have a diagnosis after months or years of not feeling well; some people discover that they have a new-found appreciation for life after being diagnosed with lymphoma and find they are better at making time for the things that are important to them.

## What can I do about these feelings?

There are many different ways that people try to cope with difficult feelings. They mainly consist of taking control of the things that you can control and finding support that suits your needs and the way you like to do things.

Here are some suggestions that other people have found helpful in the past:

- **Find out about your lymphoma** and its treatments so that you understand the choices you have to make and are forewarned about the effects of the treatment. Having this knowledge will make you feel more in control.
- **Try to face the thoughts**, events or conversations you are worried about. The more you avoid something, the more worried you can become about it. If this is difficult for you, there are people to talk to (see below).
- **Talk through your feelings and fears** – all your 'what ifs'. It is often easier to talk to someone outside the family, so perhaps approach a supportive friend or ask in the clinic if there is someone you could see. If you prefer the phone, we have a freephone helpline (0808 808 5555) if you would like to talk to someone about any aspect of your lymphoma. Other phone and internet helplines are mentioned at the end of this article.
- **Find a time to relax** every day and focus your attention on the present moment. By focusing on the here and now, living in the moment and not in fear of the future, you might feel more in control and less anxious. Some people find complementary therapies help them to relax and feel more in control, but always make sure you are seeing a qualified therapist who has experience of treating people with cancer. You should also let your medical team know about any therapies you are thinking of having.
- **Do the things that work for you** – think of the activities and hobbies that were important to you before your diagnosis and try to keep these interests going if they are not too tiring and you are still enjoying them.
- **See the people you want to see**, speak about what you want to speak about. It is fine to change the subject if you don't want to talk about something; it's OK to avoid some people.

## **Not being on treatment – living with uncertainty**

Many people with lymphoma spend considerable periods of time on 'watch and wait', when their doctors don't think treatment is required yet or when treatment has finished but they continue to go for regular check-ups. This can often be the hardest time emotionally. It is very difficult to be told you have a malignant condition but that you won't be having any treatment for it until it progresses in some way.

Periods after treatment, during which you are being followed up in the clinic, can also be difficult. While you are having treatment you are busy focusing on your tests, treatments and assessments – living very much in the present, looking forward to the treatment being finished. When you are in remission but going for follow-up checks you can feel isolated, unsupported, suddenly much more anxious about whether the treatment has worked. Life might outwardly be 'getting back to normal' but it will never be the same again and this can be difficult to adjust to.

This is a time when you might feel the need to share your feelings with friends or other people who are or have been in a similar situation. Your medical team would be able to advise you whether there is a Macmillan cancer support centre or other support group in your area and some people find these helpful. We have a network of support groups throughout the country, a buddy scheme and an interactive website with a messageboard and chatroom. Contact us by phone or via our website to find out what is available nearby, or just to talk to someone.

## **What if the lymphoma comes back?**

If your lymphoma does come back this can bring back the whole range of emotions you felt when you were first diagnosed. You might even feel worse this time. These emotions are no easier to cope with second or third time around, even if the doctors feel that a cure is possible with further treatment and start to plan this with you.

This time, once again, you will need to call on the resources you found helpful last time. It is vital to recognise that what you are feeling is natural and to ask for any help you need with the emotional side of your relapse.

## **What to do if you are having difficulty coping**

It is very common for people with lymphoma and their partners and family to have strong emotions. Many people manage to cope with them with the help of family, friends and their medical team. Some people, however, find that the intensity of their feelings is making it difficult for them to get on with their daily life or to cope with their treatment. This doesn't mean that they have failed in any way. It is just the way they feel.

If you feel like this or think that you might be getting very depressed – sleeping badly, being tearful, feeling hopeless – mention it to your doctor. If they think it would be helpful they would be able to prescribe some temporary medication or arrange for you to get specialist help, for example from a psychologist or a counsellor who specialises in helping people affected by cancer. Being depressed does not mean that you are failing yourself or your family in any way and the best thing you can do if you feel this way is to seek help.

## Conclusions

- Having too little or too much information about your illness and treatment can cause problems. Think carefully about what you want to know and ask for information from your doctors and medical team.
- Feeling worried, sad, guilty or angry is very common and is quite normal after being diagnosed with lymphoma or if your lymphoma comes back. Try to accept these feelings as a normal part of your illness and recovery. Use some of the suggested ways of coping to help.
- You will probably experience a lot of changes in your life as a result of your lymphoma. Knowing what to expect, knowing when you need help and who to turn to can make this a bit easier.

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## More information

The Lymphoma Association has a wide range of booklets and information sheets on all aspects of lymphoma, including the emotional and practical difficulties that can arise. Visit our website at [www.lymphomas.org.uk](http://www.lymphomas.org.uk) or telephone our freephone helpline on 0808 808 5555 if you would like to receive any of this information or if you would like to talk to someone about your lymphoma.

## Other useful organisations

### Macmillan Cancer Support

Macmillan provides information and support for patients and carers.

89 Albert Embankment

London SE1 7UQ

☎ 0808 808 00 00

[www.macmillan.org.uk](http://www.macmillan.org.uk)

### Maggie's Centres

At Maggie's Centres you can access information, benefits advice and emotional or psychological support. They are located throughout the country and also have online forums.

8 Newton Place

Glasgow G3 7PR

☎ 0300 123 1801

[www.maggiescentres.org](http://www.maggiescentres.org)

## Cancer Counselling Trust

Although their office and free counselling service is now closed due to financial constraints, the Cancer Counselling Trust still has a website with useful links to their experienced counsellors and informative articles on the psychological impact of cancer.

[www.cancercounselling.org.uk](http://www.cancercounselling.org.uk)

## Further reading

Hutton D. *What can I do to help? 75 practical ideas for families and friends from cancer's frontline*. 2nd edition. 2010. Short Books Ltd, London.

Buckman R. *Cancer is a word, not a sentence*. 2007. Collins, London.

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