

Live your Life

Living with and beyond lymphoma

Module 5: Practical aspects of living with lymphoma





I like to have something planned to look forward to. I think carefully about where I travel to, either staying within the UK or going to a country where I'm fairly confident there is good medical care available if I need it.

Nuala

Module 5: Practical aspects of living with lymphoma

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Notes

You can use this space to make any notes from module 5 of the Live your Life workshop.

Coping with side effects of treatment

It takes time to recover after treatment for lymphoma and you might have side effects that continue after your treatment is finished. We cover some of these in this section, and you can find more information on our website.

- Cancer-related fatigue – page 94.
- Cancer-related cognitive impairment (chemo brain) – page 98.
- Sickness and vomiting – page 100.
- Peripheral neuropathy – page 101.

Side effects of treatment can have a significant impact on your day-to-day life, practically and emotionally. Speak to a member of your medical team for advice about how to cope with any side effects you experience.



See our website for more information about side effects of treatment, including additional information on risk of infection, changes in the blood (such as anaemia and neutropenia), bowel changes, hair loss, skin changes and sore mouth (oral mucositis).

Cancer-related fatigue

Cancer-related fatigue is a type of extreme tiredness that can be physical, mental and emotional. It affects a lot of people who have, or have had, cancer. People often use words like 'exhausted', 'debilitating' and feeling 'drained of energy' to describe their fatigue.

Usually, fatigue improves over time, and although there is no treatment for it, there are things you can do that might help to manage it.

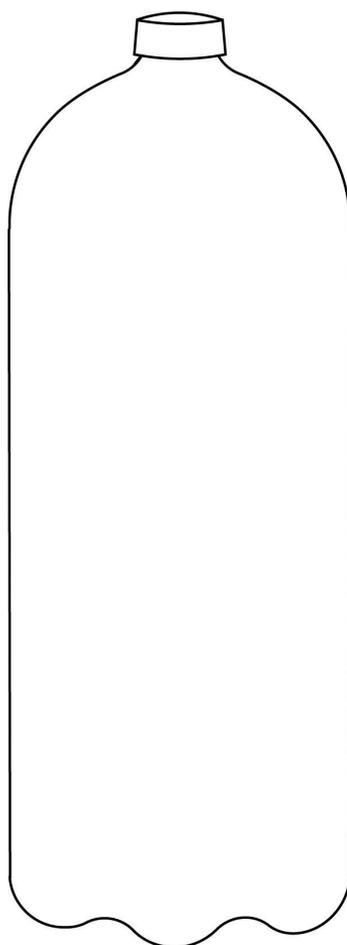
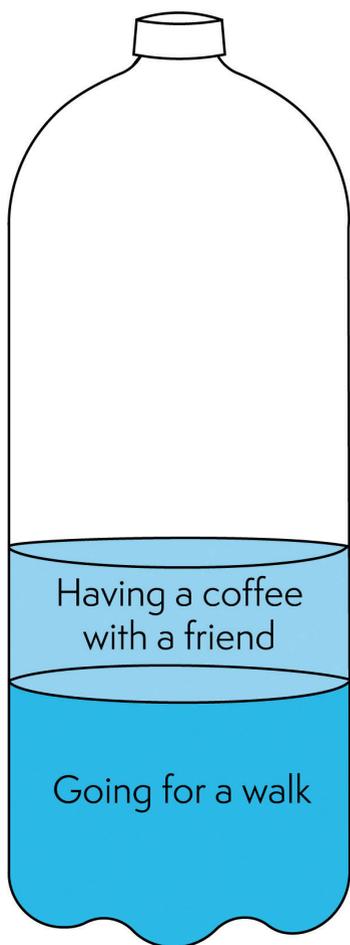


Tips to help reduce fatigue

- Take regular light physical activity, such as walking, and allow time to rest afterwards.
- Eat a healthy diet that gives you the energy you need.
- Build relaxation into your day.
- Prioritise the tasks and activities that are important or enjoyable to you – you could ask family or friends to help with other things.
- Rest between activities.
- Have a regular sleep pattern. Search 'sleep hygiene' at www.mentalhealth.org.uk for a guide to help improve your sleep.
- Try a complementary therapy like massage, yoga or acupuncture.



Imagine your energy capacity for each day as a bottle. Use the empty bottle on the right to plan your day according to how much energy each activity takes. The bottle on the left is an example.



Explaining cancer-related fatigue to people

It can be difficult to explain how cancer-related fatigue feels to people who haven't experienced it. Christine Miserandino developed 'The Spoon Theory' as a way to describe the impact of her health condition (lupus) on her day-to-day life. The theory uses spoons to represent units of energy. People with other health conditions, often use it to help explain cancer-related fatigue to their friends and family.

The key points of spoon theory are:

- With cancer-related fatigue, you have only a certain number of 'spoons' available to you at the start of each day.
- Every task and activity uses one or more spoons. For example, you start the day with 12 spoons. Having a shower might take up 2 spoons, and meeting a friend for coffee takes up 4 spoons.
- When your spoons for the day are gone, they're gone, so it's important to plan and to use them wisely. There might be times when you could borrow a spoon from the next day, but it means that you'll have fewer available to you when tomorrow comes.

Search 'spoon theory' on our website for more information.



For times when your energy is low, consider tasks or activities that you could ask someone else to do.

Cancer-related cognitive impairment ('chemo brain')

Cancer-related cognitive impairment (CRCI) describes a change in thinking processes (cognitive functioning), for example memory and attention. Although it's often known as 'chemo brain', it can affect anyone with cancer, whether or not they've had treatment, with chemotherapy or any other cancer treatments.

People with CRCI often describe feeling 'hazy' or being in a 'mental fog'. You might have difficulties recalling names and dates, concentrating on everyday tasks, planning and multi-tasking. Following a conversation or finding the word you want to use might be hard too.

Usually, symptoms improve between about 6 months and 2 years of finishing treatment. However, for some people, they go on much longer.

Tell your doctor or nurse if you're experiencing CRCI. They can check for and treat any underlying causes such as anaemia or infection, and can offer advice in managing symptoms.



Tips for coping with cancer-related cognitive impairment

- Try to focus on one thing at a time.
- Be patient with yourself, particularly with things that need a lot of attention.
- Find somewhere quiet to focus on a task or conversation.
- Note things down. Leave yourself written reminders or set up alerts on your phone.
- Make visual links to help you remember things. For example, if you're on your way to the local shop to buy some milk and bread, you could picture a bottle of milk with legs carrying a loaf of bread.
- Consider letting people know about your difficulties. For example, it might help to ease pressure if it's hard for you to find the words you want during conversations.
- Find ways of managing stress and fatigue as these can also affect your thinking processes.
- Try saying out loud what you are doing to help you remember. For example, 'it is Monday morning and I am locking the back door'.

Sickness (nausea and vomiting)

Sickness is a common side effect of many treatments for lymphoma, and stress and anxiety can worsen it. You might experience feeling sick (nausea), being sick (vomiting) or retching or dry heaves.

Tell your medical team if you feel sick. There are lots of anti-sickness medications (antiemetics) they can prescribe and they're usually more effective if you start them early. Even if one type doesn't work for you, another one might.



Tips for coping with sickness

- Include ginger in your diet. For example, you could try ginger beer, ginger tea, ginger biscuits, ginger cake or root ginger.
- Eat foods you like, but avoid your favourites, in case you start to associate them with sickness.
- Try wearing acupuncture (travel sickness) bands on your wrists.
- Try behavioural or meditative techniques, such as distraction and relaxation. Visit nopanic.org.uk relaxation-technique for an example.

Peripheral neuropathy

Some treatments can affect your nerves. This is known as peripheral neuropathy and can cause symptoms like pain, 'pins and needles' (pricking, tingling or numbness of the skin), a burning sensation, and increased sensitivity to touch and temperature. You might also have difficulty with 'fiddly' tasks that need fine movements, such as doing up buttons or tying shoelaces.

For most people, symptoms improve over time, although this can take months or even years. If you experience peripheral neuropathy, you could see whether a hospital physiotherapist could suggest exercises to help reduce symptoms.



- **If you drive, the Driver and Vehicle Licensing Agency (DVLA) says that you must tell them if you are diagnosed with peripheral neuropathy. You can download a form to do so on the UK government's website. Search 'peripheral neuropathy' at gov.uk**
- **Find out more on the NHS website. Search 'peripheral neuropathy' at nhs.uk/conditions**



Tips for coping with peripheral neuropathy

- Avoid alcohol as it can affect nerve functioning.
- Use a thermometer to make sure baths and washing up water are at a safe temperature.
- If your symptoms affect your fingers and toes, flex and stretch them for a few minutes throughout the day. You can also try gently massaging them.
- Wear gloves and thick socks in cold weather.
- Wear slip-on shoes, or ones with an easy fastening if tying shoelaces is difficult.
- Avoid putting pressure on parts of your body for too long. For example, don't sit with your legs crossed for a long time.
- Wear gloves for activities and tasks such as gardening, washing up and using the oven.
- Reduce the risk of tripping over by wearing well-fitting flat or low-heeled shoes and keeping the floors in your home clutter-free.
- Some people find acupuncture helps to relieve symptoms of peripheral neuropathy.

Finances

Under the Equality Act 2010, a diagnosis of cancer automatically meets the government's definition of disability. There are some sources of financial help for people with a disability.

As there is a range of government financial support, it's a good idea to seek professional guidance on what you might be entitled to.

- Citizens Advice have benefits advisors. Find your nearest branch at citizensadvice.org.uk. Some have a partnership with Macmillan; find out more from your local branch.
- The government website has information about benefits. Visit gov.uk
- Macmillan Cancer Support offers information about financial support for people who are living with or caring for someone with lymphoma. Visit macmillan.org.uk
- Maggie's have benefits advisors to help you understand what support might be available to you and to apply for it. Visit maggies.org
- Young Lives vs Cancer offers free welfare advice to young people aged up to 25 years. Visit younglivesvscancer.org.uk



As well as government schemes, there might be charities and other local organisations that provide grants (one-off payments). Benefits advisors at your local Citizens Advice and your clinical nurse specialist are good people to ask. You could also get a rough idea of what you might be entitled to through the benefits calculator available at entitledto.co.uk

A diagnosis of cancer also means that you are entitled to free prescriptions. Ask your GP for a medical exemption certificate.

Under the Healthcare Travel Costs Scheme (HTCS), you might also be entitled to claim a refund for your travel costs if you receive certain welfare benefits and you're referred for tests or treatment. You can read more about this scheme and eligibility criteria on the NHS website.

You can also ask at your hospital reception or information desk if they offer any other help with cancer-related costs. For example, some hospitals offer free or reduced parking charges for people who are having cancer treatment.

Work, study and training

You're likely to need to take some time out of work, study or training during treatment, and probably for a little while after finishing treatment.

If you're employed, speak to your HR department or line-manager about how they can support you.

By law, your employer must consider making adjustments that help you to continue with your work, studies or training after a diagnosis of lymphoma – this applies for the rest of your life.

Depending on the type of work you do, this could include:

- changing your working pattern – for example, working fewer hours or starting later to avoid busy commuting times
- working some or all of your hours at home
- making changes to your duties, for example, taking a less physical role
- making adjustments, for example, fitting a wheelchair ramp or providing you with any equipment that could help you
- allowing time off for medical appointments.

You could have a 'phased return' (which is an example of a reasonable adjustment), starting with shorter days or weeks. You might also start back with fewer responsibilities. Be patient with yourself and build up gradually.

If you're in education, your school, college or university, might ask for a letter from your hospital team to tell them about your lymphoma and how it affects you. Your education provider should be as flexible as possible, within the limitations of the exam boards.



- **Search 'working' on our website at lymphoma-action.org.uk for a video that gives tips for working after lymphoma.**
- **Macmillan Cancer Support has information about working with and after cancer. Search 'work and cancer' at macmillan.org.uk**
- **Working with Cancer offers coaching support and advice to people affected by cancer to get back into work. Visit workingwithcancer.co.uk**
- **Teenage Cancer Trust has information and advice for people aged 13 to 24 about returning to studies after cancer. Search 'return to education' at teenagecancertrust.org**
- **If you're a young person, search 'back to work' or 'back to education' on the Young Lives vs Cancer website at younglivesvscancer.org.uk to help plan your return to work or education.**

Holidays and travel

Many people plan a trip away after treatment as something to look forward to. There's no reason you shouldn't, but check the safety of your plans with your consultant before you book.

Keep in mind that for a while after treatment, your skin might be more sensitive to sun damage. For this reason, you might be advised to wait a while before visiting a hot country. It's also a good idea to use a sunscreen with a sun protection factor (SPF) of 30 or higher and to choose one that protects against both UVB and UVA rays.

Most doctors advise against travelling to another country while on treatment for lymphoma. This is because of the increased risk of infection, possible delays in getting medical treatment and any language differences that could cause communication difficulties.

If you're travelling outside of the UK, you might need vaccinations. Some need to be given well in advance (at least 8 weeks) to work properly, so seek advice early. Your GP or local travel clinic can advise you on which vaccinations you need. Check with them that these are safe for someone who has, or has had, lymphoma.



Find out more about travel vaccinations and other safety precautions on our website. Search 'travelling outside the UK' on our website at lymphoma-action.org.uk

Travel insurance

It's important to arrange suitable travel insurance before you go.

Travel insurance can be expensive for people who have had a diagnosis of lymphoma. This is because insurance companies work out the cost of the cover (premium) based on how likely it is that someone will make a claim.

- Most companies won't offer you insurance if you're still having treatment.
- Many companies will ask you to wait for a set amount of time (often 12 months) after finishing treatment before they'll offer you cover.

If you're on maintenance therapy, some companies class you as 'currently having treatment' but others might not.

Let your travel insurance company know if your health changes before you travel. This is important because your cover might not be valid if you don't.



Travel tips...

...for finding travel insurance

- Shop around for the best price – online quotes can give a good starting point, though you'll need to speak to the company and answer questions about your health before you can get an exact price.
- Ask your clinical nurse specialist or a member of your medical team if they know of companies that have provided cover to other people they've treated. You might also be able to ask other people affected by lymphoma if they can suggest any companies to try.
- Read the small print to find out exactly what your policy covers and for any exclusions.

...for travel safety

- If you're taking medication, pack extra, and split between bags in case one gets lost. Your GP can write a letter to explain the situation to security staff.
- Use insect repellents and mosquito nets where necessary to protect yourself from mosquitos.
- Make sure the water you drink is sterilised – note that bottled water isn't always sterile. An easy way to sterilise water is to boil it.



Action plan to help me stay well.

Action	How often
Sign up for any screening programme invitations, to maintain checks on different aspects of my health	Attend appointments in line with screening programme schedule

Information and support

If you'd like to talk to someone about anything to do with lymphoma, get in touch.



Call our **Helpline** (freephone) Monday to Friday, 10am to 3pm, on 0808 808 5555. You can also use Live Chat on our website



Join one of our peer support services such as **Support Group, online support meeting** or **closed Facebook support group**. Find one at lymphoma-action.org.uk



Use our **Buddy Service** to share experiences with someone in a similar situation to you. Call our Helpline for details



Visit lymphoma-action.org.uk/TrialsLink to search for clinical trials that might be suitable for you



Check out our **YouTube channel** to watch personal stories and medical films

See our website for full details of our services. For our latest news and updates, follow us on social media:



@LymphomaAction



lymphoma_action



If you're interested in finding out more about any of the topics in this book, we have lots more information available on our website.

We also produce a number of books, which are available free of charge. In particular, you might find the following books helpful:

- *Introduction to lymphoma*
- *Living with and beyond lymphoma*
- *Active monitoring (watch and wait) for lymphoma*
- *Caring for someone who has lymphoma*

We also have some wellbeing videos available to watch. Search 'wellbeing videos' on our website.

Find our full range of books and information, including accessible information and Easy Reads, at lymphoma-action.org.uk/Books or call 0808 808 5555 for more information.

Useful organisations

We list some organisations below that you might find helpful. You can find more useful organisations on our website. If you don't find what you're looking for, please get in touch through our Helpline Services (see page 112).

Cancer Research UK has information about cancer, including about treatment and coping strategies.

www.cancerresearchuk.org

Citizens Advice provide free advice on matters such as housing, consumer, money and legal issues.

www.citizensadvice.org.uk

Every mind matters – NHS is a website from Public Health England with tips and advice for good mental health.

www.nhs.uk/every-mind-matters

GOV.UK is the UK government website. It outlines the financial benefits that people affected by cancer and their carers might be entitled to.

www.gov.uk

Look Good Feel Better helps people to manage the visible side effects of cancer treatment with free group and self-help skincare and make-up workshops

www.lookgoodfeelbetter.co.uk

Macmillan Benefits Advice Service offers financial advice, including welfare benefits, housing, work and debt to people with cancer and their carers.

Macmillan Cancer Support provides support for people affected by cancer from diagnosis through treatment and beyond.

www.macmillan.org.uk

Maggie's gives practical, emotional, financial and social support to people with cancer, their family and friends.

www.maggies.org

Mental Health Foundation has information about mental health, including resources designed to introduce techniques to support mental wellbeing.

www.mentalhealth.org.uk

Mind offers support and advice in relation to mental health. You can email their infoline at info@mind.org.uk or call on 0300 123 3393.

www.mind.org.uk

NHS website has health information.

www.nhs.uk

NHS inform is a health information service from NHS Scotland covering health and welfare, and including self-help resources that are free to access.

www.nhsinform.scot

Relate is the UK's largest provider of relationship support. Their services include information, workshops and counselling.
www.relate.org.uk

Samaritans offer emotional support to anyone who is struggling with difficult feelings. Their service runs 24 hours a day, all year round. Call 116 123 or email jo@samaritans.org
www.samaritans.org

Shine Cancer Support offers support for people in their 20s to 40s who have been diagnosed with cancer.
www.shinecancersupport.org

Shout offers support to anyone struggling to cope. They have a free and confidential text service available 24/7. Text 85258
www.giveusashout.org

Teenage Cancer Trust offers information and support for young people living with cancer and for their families.
www.teenagecancertrust.org

Working with Cancer helps employees, employers, the self-employed, job seekers, people who are self-employed, and carers to manage cancer and work.
www.workingwithcancer.co.uk

Young Lives vs Cancer offers clinical, emotional and practical support to children and young people with cancer, and to their families.
www.younglivesvscancer.org.uk

About our information

Our information is evidence-based, approved by experts and reviewed by users. By keeping up-to-date with latest developments, we ensure that our information stays relevant and reflects current practice. Learn more at lymphoma-action.org.uk/HealthInfo

How you can help us

Volunteering is at the heart of what we do. If you'd like to volunteer with us, visit lymphoma-action.org.uk/Volunteering

We continually strive to improve our resources and are interested in any feedback you might have. Please visit our website at lymphoma-action.org.uk/BookFeedback or email us at publications@lymphoma-action.org.uk with any comments. You can also call our Information and Support team on 0808 808 5555.

References

The full list of references is available on request. Please email publications@lymphoma-action.org.uk or call 01296 619400 if you would like a copy.

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This book is part of Lymphoma Action's Live your Life peer-led, self-management workshops, but can also be used on its own. It is designed to support you to live well with and beyond your lymphoma, and includes lots of information, suggestions and places for you to write your own notes.

Lymphoma Action is the UK's only charity dedicated to lymphoma, the fifth most common cancer. Our mission is to make sure no one faces lymphoma alone.



Helpline (freephone) **0808 808 5555** (Mon to Fri, 10am to 3pm)



Email **information@lymphoma-action.org.uk**



Visit **www.lymphoma-action.org.uk**



Live Chat via our website (Mon to Fri, 10am to 3pm)

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✓	Evidence-based
✓	Approved by experts
✓	Reviewed by users