

Live your Life

Living with and beyond lymphoma
Workbook to accompany workshops

Module 5: Practical aspects of
living with lymphoma





Within a short time, I had a eureka moment. I realised I was still trying to live my old way of life, and the emotions I was feeling was a form of bereavement for that previous life. With this new perception on fighting, living and working with lymphoma, I use the knowledge and information gleaned from the workshop to create realistic personal action plans and achievable goals.

Simon, diagnosed with stage 4 nodal marginal zone lymphoma





Although many would describe my treatment as successful, life has changed. There is no point trying to 'pick up where I left off' as I am a different person both physically and emotionally. Life has changed – and, surprisingly, often for the better.

Phil, diagnosed with diffuse large B-cell lymphoma

Module 5: Practical aspects of living with lymphoma

This module is one of a series taken from our workbook 'Live your Life - living with and beyond lymphoma'.

There are five modules in total:

- Know your lymphoma
- Coping with the emotional aspects of lymphoma
- Exercise and staying active
- Diet and nutrition
- Practical aspects of living with lymphoma

You can download all of the modules, or the complete workbook, at www.lymphoma-action.org.uk/lylworkbook



**Use this space to transfer your notes from Module 5
of your Live your Life workshop**



Action plan

Action	When
<i>Example: Register for screening programme</i>	

If I am worried about side effects or late effects I should contact:

Name of health professional	Contact details

Coping with side effects of lymphoma treatment

It takes time to recover after treatment for lymphoma and you might have side effects that continue after your treatment ends. Some are covered here.

Cancer-related cognitive impairment ('chemo brain')

'Chemo brain' describes changes to memory, thinking processes and concentration that affect some people with cancer. Most people get better between 6 months and 2 years after treatment ends but about 1 in 3 people have symptoms that last longer.



Tips for coping with 'chemo brain'

- Pace yourself: keep life simple and don't take on too much.
- Be organised. Do one thing at a time and don't try to multi-task.
- Put important things in one place every time you put them down.
- Write things down – in diaries, sticky notes or on your phone.
- Eat a healthy diet, exercise and keep your mind active.
- Try relaxation techniques.
- Tell your family, friends and colleagues how they can support you.

Peripheral neuropathy

Some treatments for lymphoma can affect your nerves, causing pain, loss of sensation and tingling, often in the hands and feet. This is called peripheral neuropathy. Symptoms usually get better within 6 to 12 months but they can last longer.

You may need to inform the DVLA if you have peripheral neuropathy. Ask your medical team for advice.



Tips for coping with peripheral neuropathy

- Flex, stretch and massage your fingers and toes several times a day.
- Avoid alcohol as it can affect nerve function.
- Wear gloves and thick socks in cold weather.
- Use gloves for gardening and washing up and oven gloves for cooking.
- Wear well-fitting, flat or low-heeled shoes.
- Check the temperature of baths and showers before you get in.

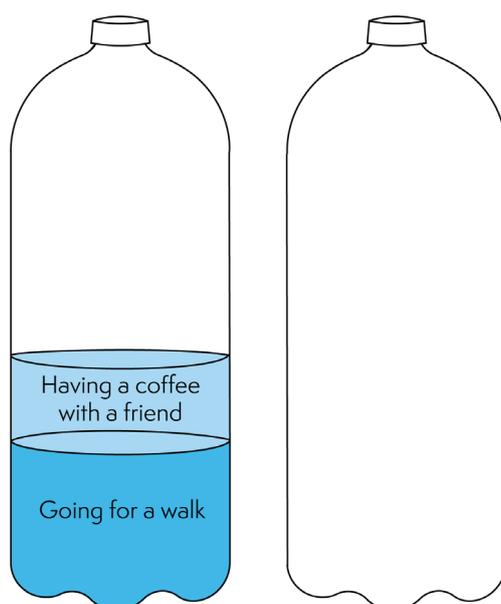
Fatigue

Cancer-related fatigue is one of the most common and troublesome effects of cancer and cancer treatment. Fatigue often lasts for months after treatment ends and it may persist for several years, although it usually gets less troublesome over time.



Tips for coping with fatigue

- Prioritise your most important activities for when you have most energy.
- Pace yourself. Don't try to do too much and plan regular short rests.
- Exercise regularly – it may seem counterintuitive but it improves fatigue.
- Eat a healthy diet.
- Try relaxation and complementary therapies.
- Keep to a regular sleep pattern.
- Ask for help when you need it.



Imagine your energy capacity for each day as a bottle. Use the diagram above to plan your day according to how much energy each activity takes.



- Visit [youtube.com/LymphomaAction](https://www.youtube.com/LymphomaAction) for videos and personal experiences about life after lymphoma.
- Search 'coping with fatigue' at www.macmillan.org.uk to download a booklet on how to deal with fatigue at work.

Late effects of lymphoma treatment

Late effects are health problems that appear months or years after treatment has finished. Your risk of late effects depends on a number of different factors, including your type of lymphoma, your treatment, your age and lifestyle. Late effects of lymphoma treatment can include:

- second cancers
- heart disease
- stroke
- lung problems
- thyroid problems
- dental problems
- eye problems.

It is important to attend all screening programmes you are called for – they are designed to pick up problems early.



Your treatment summary should tell you what late effects you're at risk of and what signs to look for. Make a note of them here.

Late effects I'm at risk of	Signs to look out for



Tips for monitoring late effects

- Get to know what is normal for you.
- Attend your follow-up appointments and screening appointments.
- Have regular check-ups with your dentist and optician.
- **If you think something is not right, visit your GP or contact your lymphoma specialist.**



For more information about side effects and late effects of lymphoma treatment, talk to your CNS, call our Information and Support team on 0808 808 5555, or search 'side effects' at www.lymphoma-action.org.uk

Early menopause and fertility

Some lymphoma treatments can reduce your fertility or cause early menopause. Your specialist should tell you if you are likely to be affected.

Early menopause can cause symptoms that are similar to lymphoma, such as night sweats or tiredness. Symptoms are more likely to be caused by menopause if you also have other symptoms of menopause, such as irregular or no periods, hot flushes or mood swings. Symptoms are more likely to be caused by lymphoma if you have other symptoms of lymphoma, such as weight loss, fever or itching.

If you're worried that your lymphoma has come back or got worse, contact your medical team straight away.

There are lots of methods to help preserve fertility, or to help you conceive if you have fertility problems. Many people go on to have a family after lymphoma treatment.

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- **The British Infertility Counselling Association website at www.bica.net provides information and support on infertility and assisted conception.**
 - **Find out about fertility treatment and its availability at The Human Fertilisation and Embryology Authority website at www.hfea.gov.uk**
 - **Visit www.fertilitynetworkuk.org for information, advice and support groups for people who are struggling to conceive.**
 - **Visit www.daisynetwork.org.uk for information and a friendly support network for women with premature menopause.**
 - **Visit www.menopausematters.co.uk for information on premature menopause, a forum and a list of frequently asked questions.**
 - **The British Menopause Society offers advice, reassurance and education for women of all ages at www.womens-health-concern.org**

Bone health

Some lymphoma treatments can cause bone thinning, particularly if you have experienced early menopause. To improve your bone health, follow the normal recommendations for a healthy lifestyle: eat a healthy diet, do not smoke, exercise regularly and keep to the guidelines for alcohol consumption.



Search 'bone health' at www.macmillan.org.uk for more information on how cancer and its treatment can affect your bones.

Travel

Many people plan a holiday to look forward to after treatment. It's a good idea to discuss your travel plans with your doctor before you book. Your skin could be more sensitive to sun damage for a while, so it might not be the best time to visit a very hot country.

If you're planning a trip abroad, you may need vaccinations. Some need to be given at least 8 weeks in advance so seek advice early. Your GP or local travel clinic can advise you. They can also tell you which vaccinations are safe for people with lymphoma. Live vaccines are not recommended.

Travel insurance

Travel insurance is more expensive for people with lymphoma because the insurance company considers you more likely to make a claim.

Most companies will not offer travel insurance while you are on treatment. Many will not offer cover until a set amount of time (often 12 months) after the end of your treatment. If you are on maintenance rituximab, some companies may class you as being on treatment but others may not.



Tips for finding travel insurance

- Shop around for the best deal.
- Ask other people with lymphoma who they've found insurance with – for example, on Lymphoma Action's forum: www.lymphoma-action.org.uk/Forum
- Read the small print to check exactly what your policy covers.
- Let your insurer know if your health changes before you travel.



- **For more information on travelling with lymphoma, visit our 'Living with lymphoma' pages at www.lymphoma-action.org.uk/LWL**
- **Find which vaccinations you need for your destination at the NHS Fit for Travel website www.fitfortravel.nhs.uk**
- **Search 'travel and holidays' at www.macmillan.org.uk for information, advice and booklets on travelling after cancer.**
- **Search 'travel' at www.abi.org.uk for general advice on buying and claiming on travel insurance from the Association of British Insurers.**
- **The National Travel Health Network and Centre's website www.nathnac.net also provides travel health information.**

Work and study

By law, you are entitled to 'reasonable adjustments' to allow you to continue to work or study after a diagnosis of lymphoma. This law protects you for the rest of your working life, not just while you're ill or having treatment.

Talk to your manager, HR department or education provider about any adjustments you may need. Examples of 'reasonable adjustments' include:

- reducing or changing your hours
- a phased return to your usual hours, starting with shorter days or weeks
- working from home
- adjusting the kind of work you do (for example, a less physical role)
- changes to your workplace (for example, installing a wheelchair ramp)
- special equipment or software you may need
- time off for medical appointments.

If you're at school, your school and local council should provide support, such as home tutoring or a hospital teaching service, to make sure your education doesn't suffer.

Financial support

Under the Equality Act 2010, a diagnosis of cancer meets the government's definition of disability and there's a wide range of financial support you may qualify for. Financial support can be complex so it's best to seek professional guidance.

- **Watch videos about working with and after lymphoma at www.lymphoma-action.org.uk/WAC**
- **Search 'work and cancer' at www.macmillan.org.uk for information about work and cancer for employed and self-employed people.**
- **Working with Cancer, at www.workingwithcancer.co.uk, is an organisation that helps people with cancer get back in to work.**
- **Search 'education and employment' at www.clicsargent.org.uk for information about taking time out of college for treatment.**
- **Citizens Advice have advisers you can contact by phone, online at www.citizensadvice.org.uk, by web chat or at your local centre.**
- **Click 'benefits' at www.gov.uk for information about the various government benefits that may be available to you.**
- **Your specialist nurse may also be able to help you access the support you're entitled to.**



Useful organisations

Cancer Research UK provides comprehensive information on all types of cancer. Call **0808 800 4040** or visit **www.cancerresearchuk.org**

Citizens Advice provides free, independent and confidential advice on benefits, housing, consumer and other problems. Call **03444 111 444** (England), **03444 77 20 20** (Wales) or visit **www.citizensadvice.org.uk**

CLIC Sargent provides specialist support for children and young people with cancer and their families. Call **0300 330 0803** or visit **www.clicsargent.org.uk**

Depression UK is a self-help organisation for people with depression. Visit **www.depressionuk.org**

Drinkaware is an independent charity that helps people make better choices about drinking. Call **0300 123 1110** or visit **www.drinkaware.co.uk**

Macmillan Cancer Support provides support and information for people with all types of cancer. Call **0808 808 00 00** or visit **www.macmillan.org.uk**

Maggie's Centres provide free support for people with cancer and their family and friends. Call **0300 123 1801** or visit **www.maggiescentres.org**

Mind provides advice and support to anyone experiencing a mental health problem. Call **0300 123 3393** or visit **www.mind.org.uk**

Moodjuice offers information, advice and self-help resources to people experiencing troublesome thoughts, feelings and actions. Visit **www.moodjuice.scot.nhs.uk**

NHS Choices provides comprehensive health information to help you make the best choices about your health and lifestyle. Call **111** or visit **www.nhs.uk**

NHS Smokefree provides motivation, information and support for smokers who want to quit. Call **0300 123 1044** or visit **www.nhs.uk/smokefree**

Shine Cancer Support offers support for adults in their 20s, 30s and 40s who have a cancer diagnosis. Visit **www.shinecancersupport.org**

The Mental Health Foundation is a UK charity that helps people understand, protect and sustain their mental health. Visit **www.mentalhealth.org.uk**

The UK Government information service outlines what benefits you might be entitled to and how to claim them. The enquiry line is no longer available. Visit **www.gov.uk**

Working with Cancer is an organisation that helps people with cancer get back in to work or to find work. Visit **www.workingwithcancer.co.uk**

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References

These are some of the sources we used to prepare this information. The full list of sources is available on request. Please contact us by email at publications@lymphoma-action.org.uk or phone on 01296 619409 if you would like a copy.

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About our information

Lymphoma is a complex type of cancer. Our award-winning information and publications can help you better understand your diagnosis, treatment and life beyond lymphoma.

Lymphoma Action's booklets give information on broad topic areas (for example they might cover all low-grade non-Hodgkin lymphomas and the types of treatment often given). They are professionally printed and bound and most are A5 size.

We offer our lymphoma information to you free of charge (UK only). If you live outside the UK, we recommend that you contact the lymphoma patient and carer organisation in your country as treatments and healthcare systems vary overseas. You can find a list of which organisations might be of help in your country on the Lymphoma Coalition website www.lymphomacoalition.org.

Lymphoma Action is committed to the provision of high quality information for people with lymphoma, their families and friends. We produce our information using nationally recognised guidelines, including the DISCERN tool for information about treatments, the NHS Toolkit for producing patient information and the Campaign for Plain English guidelines. Lymphoma Action is a certified member of The Information Standard independent quality assurance scheme, which is supported by the Department of Health.

Our publications are written by experienced medical writers, in close collaboration with medical advisers with expertise in the appropriate field. The most relevant references are listed in the publication. A full list of sources is available on request.



Information and support

If you'd like to talk to someone about anything to do with lymphoma (including how you feel), get in touch.



Call our Information and Support team Monday to Friday on 0808 808 5555. You can also use Live Chat on our website



Come to one of our support groups. Find one near you at www.lymphoma-action.org.uk/support-groups



Join our online forum to chat with others who are affected by lymphoma



Get in touch with a buddy, someone affected by lymphoma



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



Like us on Facebook



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Follow us on Instagram

How you can help us

We continually strive to improve our resources for people affected by lymphoma and are interested in any feedback you might have about this booklet. Please visit our website at www.lymphoma-action.org.uk/Book-Feedback 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.



We produce other publications that give information about lymphoma and what to expect from treatment. Visit our website at www.lymphoma-action.org.uk or call 0808 808 5555 for more information.

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Check our website for the most up-to-date details of our services, including opening times.



This booklet has been researched and written by Lymphoma Action, the only UK charity dedicated to those affected by lymphoma.

We would like to thank our incredible supporters whose generous donations enable us to offer all our essential support services free of charge. As an organisation we do not receive any government or NHS funding and so every penny received is truly valued. From everyone at Lymphoma Action and on behalf of those affected by lymphoma, thank you.

To get involved in fundraising for us or to make a donation towards our work please visit www.lymphoma-action.org.uk/Donate

This workbook complements the Live your Life workshop. It provides practical advice and information about living with and beyond lymphoma and has space for you to record information about your own lymphoma experience.

Lymphoma Action is a charity that has been providing information and support to people affected by lymphoma for over 30 years. We're here for you.



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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