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Lymphoma is the fifth most common cancer in the UK, and there are sixty different types of the disease. Lymphoma Action, the UK charity dedicated to providing expert information and support for those affected, estimates that 2,000 cases of so-called Hodgkin lymphoma are diagnosed every year in the UK. More common is non-Hodgkin lymphoma, with around 4 in every 100 cancer diagnoses being due to the disease. Blood specialist Professor Graham Collins has co-authored national guidelines on lymphoma, and here answers some key questions.

What is lymphoma and what are the different types?

Lymphoma is a type of cancer, even though it doesn't have the word 'cancer' in its name. The cells that go wrong in lymphoma are cells of the immune system called lymphocytes. So I think it's best regarded as a cancer of the immune system. Lymphocytes spend most of their time in lymph glands (which we have throughout the body) and the spleen so commonly the first symptoms are those of swollen and enlarged lymph glands.

There are many different types of lymphoma – over 60! In broad terms they are divided into Hodgkin and non-Hodgkin lymphoma, named after the person who first described it. Hodgkin lymphoma typically affects young people (with a peak age of 15-35 years) and is highly curable with chemotherapy and sometimes radiotherapy. Non-Hodgkin lymphoma is split into low grade (or indolent) and high grade (or aggressive forms). High grade forms can grow quickly and make people unwell, but are treatable and in many cases curable with chemotherapy and immunotherapy. Low grade forms are very slow growing and most people are well at diagnosis (simply having a lump). Although they are not considered curable with most standard treatments, they do have a very good outlook.

How is it different to leukaemia?

The difference between leukaemia and lymphoma is rather blurred. However in general, leukaemia is a cancer of the blood and bone marrow resulting in abnormal blood counts, whereas lymphoma is a cancer of lymph glands and tends to result in lumps. There is an overlap though as the commonest form of leukaemia (called chronic

lymphocytic leukaemia or CLL) is biologically speaking really a low grade non-Hodgkin lymphoma.

Veteran TV presenter Michael Aspel [5] has lived with non-Hodgkin lymphoma for 20 years and controls it with a tablet. Is this common?

Low grade forms of non-Hodgkin lymphoma are very slow conditions and life expectancy with these conditions is typically 20 years or more. Often they don't need to be treated but simply kept an eye on (called 'watch and wait' or 'active surveillance'). Sometimes they can cause problems and treatment with usually fairly gentle chemotherapy and immunotherapy (sometimes radiotherapy) is often very effective at getting the lymphoma back in remission. Remission isn't cure though and the disease does relapse, but often many years later and treatments at that point still are often effective. Treatments now are more typically into a vein (intravenous) but sometimes tablet forms of treatment are used. I often do say to patients though that tablets are not necessarily milder than intravenous treatments. It is what is given that is important, not necessarily how it is given.

What's in the pipeline for new treatments?

There is a lot of research looking into new treatments for lymphoma and several active new drugs are in the pipeline. One to mention is CAR T-cell therapy. CAR stands for 'chimeric antigen receptor'. Essentially, a patient has some T-cells (normal immune system cells) removed from the body in a fairly simple process called apheresis. These are then sent off to a pharmaceutical company who genetically engineer them so that, as well as recognising micro-organisms which is their usual job, they also recognise the patient's lymphoma. The cells are grown up and sent back. After some preparatory chemotherapy, the patient then receives the cells back intravenously, a bit like having a short blood transfusion. The cells go on a search and destroy mission to find lymphoma cells and kill them. This treatment is very effective for certain forms of lymphoma and is available on the NHS for some types of high grade non-Hodgkin lymphomas which have relapsed quickly after first line treatment. They are also active in low grade forms but not currently available on the NHS for this.

Another new form of treatment is called bispecific antibody treatment. We all have many antibodies in our bloodstream. Each antibody has two 'arms' but they bind the same thing. It's now possible to make antibodies which bind two different things. The bispecific antibodies in use now have one arm which binds a lymphoma cell and the other arm binds a T-cell, bringing it in close proximity to the lymphoma cell and allowing it to attack the cancer. Again these drugs are very effective in certain forms of lymphoma and we can use them on the NHS for relapsed high grade non-Hodgkin lymphoma.

Both of these new forms of treatment are good examples of immunotherapy, where steps are taken to harness the power of the body's own immune system [6] to fight cancer.

Interviewed for *Readers' Digest* [7], some young people reflect on life after treatment and all that comes with long-term cancer survivorship. What are the challenges?

When I see a patient with lymphoma, one thing I warn them about is that psychologically there are two particularly challenging times. One is at diagnosis – not surprisingly. However the other is at the end of treatment. Patients go from a situation where they are seen regularly by the medical and nursing teams, having scans, often being given good news, to suddenly only seeing the team every 3-6 months and not knowing how to interpret odd symptoms they are experiencing. It can feel like they are being told to 'get on with their life now' and it's very hard to know what this looks like after treatment.

One common challenge is fatigue or tiredness. This can be quite profound at the end of treatment and can last some months. Indeed some people never feel they quite get back to normal. There is no treatment specifically for

fatigue, but graduated exercise programmes can be helpful. It's also very common to experience other symptoms which on occasion can feel similar to the initial lymphoma symptoms such as sweats or an itch. Usually these symptoms do not mean the lymphoma is coming back, but it's always a good idea to contact the specialist nurse who would have been assigned at diagnosis, to chat through any issues such as these.

A cancer diagnosis comes with other issues too. It can lead to financial pressures, especially for those who are self-employed. It can also lead to pressure on relationships. More positively, sometimes a cancer diagnosis can lead to re-evaluation of priorities in life such as a re-evaluation of work-life balance.

Depending on the type of treatment received, there may be some longer term medical issues which need addressing as a consequence of the treatment. Young people treated for Hodgkin lymphoma for example may have reduced fertility or an increased risk of heart disease or a second cancer diagnosis. Depending on the situation, enhanced cancer screening programmes may be needed, or cardiology reviews.

Is finding a 'new normal' possible?

A new normal is possible. However this is best achievable with support of family and friends, supportive employers and also charities such as Lymphoma Action who have created programmes such as 'Live your Life [8]' which can really help patients re-adjust.

What advice would you give to someone newly diagnosed?

At diagnosis it's really important to find reliable sources of information. The internet can be very helpful but do use reliable websites such as Lymphoma Action [9], Blood Cancer UK [10] and Macmillan [11]. There is also a lot of very unhelpful information out there and it's important to speak with your doctor and specialist nurse about the best treatment strategy for a given lymphoma.

Other advice I would suggest is always take someone with you to the initial consultation as it's hard to take in everything by yourself. Be honest with your family about the diagnosis – it rarely helps to keep things from family members such as children, although there is support available for explaining a cancer diagnosis to young children. Do also speak with your employer early so they can offer the right help and support when needed.

Whilst a diagnosis of lymphoma is always difficult, do remember that the outcomes are generally good and there is cause for optimism.

MEDICAL JOURNALISTS' ASSOCIATION

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