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Understanding Supported Self-Management

Haematology Services

Information for patients with lymphoma

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What is Supported Self-Management (SSM)?

SSM offers you support and education to help you take charge of your health and wellbeing. It provides follow-up after treatment for lymphoma. Follow-up is important to ensure that there are no signs that your lymphoma has relapsed (come back).

In the past, follow-up involved coming to the hospital to have a face-to-face discussion with a doctor, who would look at your blood test results and discuss any side effects of treatment. SSM is an approach to cancer treatment follow-up that replaces the need for you to attend clinic appointments and have unnecessary tests and investigations whilst you are well.

What are the benefits?

Routine clinic visits and investigations often cause anxiety and stress for individuals who are well following their cancer treatment. SSM allows patients to put their cancer experience behind them and focus on getting back to their normal lives. They tend to worry less about blood test results and clinic appointments and also avoid the inconvenience that these visits may cause.

SSM allows you to be actively involved in your recovery from lymphoma with support. Any concerns that you have can be dealt with quickly. Routine follow-up appointments can sometimes delay us finding out that the lymphoma has relapsed as people tend to wait for their appointment before raising any concerns.

If patients on the SSM programme notice any new symptoms they can contact their Clinical Nurse Specialist (CNS) to discuss their concerns, and an appointment to see a doctor in the next available clinic can be arranged.

Does SSM improve care?

There is no evidence to suggest that routine clinic appointments and blood tests detect relapse earlier or improve life-expectancy. It is patients themselves who tend to identify when new problems are developing.

The SSM approach is encouraged by the Department for Health and also cancer support charities such as Lymphoma Action (Free Support line: Tel 0808 808 5555) and Macmillan Cancer Support (Free

Support Line: Tel 0808 808 0000). These charities can provide you with additional support and advice about this form of follow-up if needed.

Who is SSM suitable for?

SSM is not suitable for everyone with lymphoma. Your clinical team will explain to you why SSM is considered appropriate for you.

What happens next for patients on SSM?

Once you have completed your treatment for lymphoma you will enter ‘follow-up’. To start with, you will attend the lymphoma clinic every three months for a review of your blood test results and a face-to-face discussion with a doctor.

After a year of these appointments, if you remain well with no signs of your lymphoma relapsing, you will enter the SSM programme. This means there will be no need for you to attend the clinic or have any further routine blood tests or scans.

During your final clinic appointment, as well as seeing a doctor, you will also have a thirty minute appointment with one of the lymphoma Clinical Nurse Specialists (CNS). During this appointment the CNS will offer you the chance to complete a Holistic Needs Assessment to help you identify any immediate concerns that you may have and, if needed, they will provide you with a care plan.

When you have finished your treatment you may wish to take part in a health and wellbeing event aimed at patients recovering from their cancer experience. Your CNS will explain which events are available and how to book onto them.

The CNS will also tell you about SSM and will explain the potential signs and symptoms that you should contact them about.

These will include:

- New lumps or swellings
- Persistent chest symptoms such as shortness of breath or a new cough that does not go away
- Abdominal swelling and unexplained discomfort or pain
- Itching all over your body that does not go away
- Drenching and recurrent night sweats

- Unexplained or unintentional weight loss (more than 10% of your body weight over a period of a few months)
- Fevers of 38 degrees centigrade with no signs of infection
- Sudden unexplained loss of mobility, new pins and needles sensation or loss of sensation, visual problems such as double vision, balance issues or confusion.

If you have any of the above or any new symptoms that are causing you concern then please contact the CNS team:

Telephone: 0116 258 5738 (Monday – Friday 9am to 5pm)

Please leave a message and your call will be returned within 24 hours (excluding Bank Holidays and weekends).

Asking for your feedback

SSM seems to be an effective way to enable patients to put their cancer experience behind them and resume a life-style similar to the one they enjoyed before their diagnosis. However, SSM is fairly new and it is important that we continue to monitor patients' experiences of SSM.

Whilst you are on SSM, we may send you a Quality of Life (QoL) questionnaire to ask you for your feedback about your experience of participating in this type of follow-up. Not everyone will be sent this questionnaire, but if you do it will be sent to you once a year until you are discharged from the lymphoma service.

How long will I be on the SSM programme?

The length of time that you will be on SSM will depend on the type of lymphoma that you were treated for and will vary between one and five years. We will let you know how long this is likely to be for you.

Once you have been on SSM for the specified length of time, providing that you are completely well with no evidence of your lymphoma relapsing, then you will be discharged from the care of the lymphoma service. This means that you will then be under the care of your GP.

When you have been discharged from our service, it is because there is an extremely low risk that your lymphoma will relapse in the future. Any concerns about any aspects of your health going forward should now be dealt with by your GP.

Some patients find the idea of Supported Self-management rather worrying. Please remember that you are not discharged from the lymphoma service during this time and that if you have any concerns or questions you can contact the Lymphoma Clinical Nurse Specialist team in the same way that you did whilst having your treatment.

Health information and support is available at www.nhs.uk or call 111 for non-emergency medical advice

Visit www.uhleicester.nhs.uk for maps and information about visiting Leicester's Hospitals.

To give feedback about this information sheet, contact uhl-tr.informationforpatientsmailbox@nhs.net

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہِ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

إذا كنت ترغب في الحصول على هذه المعلومات بلغةٍ أُخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો.

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email uhl-tr.equalitymailbox@nhs.net

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