

Ocular melanoma patient initiated follow up (PIFU)

Information for patients



This booklet explains what the ocular melanoma patient initiated follow up (PIFU) service is and how it works. It contains all the information you need to contact the ocular melanoma team and book an appointment if you are worried.

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Your personal details

Name:

Hospital number:

Oncology consultant:

Clinical nurse specialist:

Support worker:

What is patient initiated follow up (PIFU)?

We have introduced a new 'patient initiated follow up' (PIFU) service to ocular melanoma care at University Hospital Southampton.

With the PIFU service you can:

- be in control of your own care with our help (known as 'supported self-management' - see page 4)
- contact the specialist ocular melanoma team at the hospital when you need support, instead of waiting for a planned appointment

Benefits of the PIFU service

In the past, people living with or after ocular melanoma have had regular hospital appointments for follow-up care. Some people found these pre-arranged appointments a source of great anxiety and not particularly helpful, unless they had something specific they wished to discuss.

On the PIFU service, you will no longer have to come in for routine follow-up appointments at the hospital. Instead, you will be able to contact us directly to arrange a follow-up appointment if you have any concerns. There is strong evidence that symptoms and concerns are addressed more quickly if you report them as and when they occur, rather than waiting for a routine appointment.

How to contact the ocular melanoma team

Once you are set up with the PIFU service, you can contact the ocular melanoma team as and when you need support or when you would like to arrange a review appointment.

There are two ways to contact the ocular melanoma team:

1. Send a message on My Medical Record: mymedicalrecord.nhs.uk
We will respond within two working days. Messages sent at the weekend will be replied to the next working day.
2. Telephone us on **023 8120 4711** or **07768 656 215**

Getting started with the PIFU service

A member of the ocular melanoma team will talk with you about the PIFU service. If you and your doctor agree that this is the right option for you, we will book you in for an introductory phone call with a member of the ocular melanoma team and/or send you an introductory slide show video.

During the call or video, we will cover the following topics:

Supported self-management

We will explain what supported self-management is and how you can take an active and leading role in your recovery with help from your specialist cancer team. We will give you the skills and confidence to self-monitor for symptoms and signs of recurrence.

My Medical Record (MyMR)

We will help you connect to My Medical Record (MyMR) and show you how to use it. Developed by University Hospital Southampton, MyMR is a free and secure online platform that is available via a website and as an app for your phone or tablet. It gives you access to information about your healthcare and connects you with your clinical team and other support services. On MyMR you can read information about ocular melanoma and contact the specialist team online.

Ocular melanoma surveillance

We will explain how your ocular melanoma surveillance is planned and what it involves.

Lifestyle choices

There are lots of things you can do to look after your own health during and after cancer treatment, such as physical activity and healthy eating.

Physical and emotional effects of ocular melanoma

We will talk about coping with the physical effects of ocular melanoma, and with the emotional impact, including stress and the fear of the melanoma recurring.

Moving forward and goal setting

We will help you to set your own goals for recovery and rehabilitation.

Ocular melanoma surveillance

You will need to have an MRI scan to check for ocular melanoma every six months for the first five years, and then once a year for the next five years.

We will send you a letter and/or a message on MyMR when your next MRI scan is due. You can have the MRI scan at University Hospital Southampton or possibly at your local hospital.

We will send you a letter and/or a message on MyMR to tell you about the result of the scan, or we may telephone you if we need to discuss the result with you.

If you have any concerns about your results, you can contact us by telephone or send us a message on MyMR. You can leave a message on the answer machine, which is checked every working day. (Please note: it is not an emergency phone line.) We will aim to contact you within one working day.

Holistic needs assessment (also known as Health MOT)

A holistic needs assessment is a survey that helps to identify any concerns or problems you may have after a diagnosis of ocular melanoma. These might include practical issues (such as work), the physical and emotional effects of cancer, or concerns relating to your relationships or family life.

You can then discuss these with the ocular melanoma team and they can give advice, help you to manage your care or recommend other help or resources.

Finding support

You may have already found that people have different ways of living with ocular melanoma. There is no right or wrong way, just what works for you. Some people prefer not to talk about it, while others find it helps to discuss their experiences.

We are here to help you get the support you need, so please ask us if you would like details of local support groups. You can also find more information about support groups and other useful contacts on MyMR.

National contacts

OcuMel UK

An ocular melanoma charity run by patients and family members.

Telephone: **0300 790512**

www.ocumeluk.org

Cancer Research UK

Cancer Research UK's patient information resources.

Helpline: **0300 123 1022**

www.cancerresearchuk.org

Macmillan Cancer Line

Free information, and practical and emotional support.

Telephone: **0808 808 0000**

www.macmillan.org.uk

NHS Choices

Includes all NHS online services and information, to help you make choices about your health.

www.nhs.uk

Citizens Advice Bureau

www.citizensadvice.org.uk

Local contacts

Southampton Macmillan Cancer Information and Support Centre

B level, Southampton General Hospital

Telephone: **023 8120 6037**

www.uhs.nhs.uk/OurServices/Cancer

Jane Scarth House

A local charity providing emotional and practical support to anyone who is affected by cancer.

Telephone: **01794 830374**

www.janescarthhouse.co.uk

Wessex Cancer Trust

A local charity providing information, counselling and complementary therapies.

Telephone: **023 8067 2200**

www.wessexcancer.org.uk

Every Mind Matters – One You

Advice about healthy living.

www.nhs.uk/oneyou

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For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **www.uhs.nhs.uk/additionalsupport**

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