NHS
The Clatterbridge
Cancer Centre
NHS Foundation Trust

Supported Self-management & Patient Directed Open Access

Haemato-Oncology

For patients with
IgG, IgA and light chain MGUS
(Monoclonal Gammopathy of
undetermined significance)

A guide for patients and carers

Contents

Personal details

Name:

CCC number:

Date of diagnosis:

Haematological diagnosis:

Consultant:

Named Nurse Specialist:

Named Support Worker:

Introducing supported self-management

Supported self-management puts you in control of your care and allows you to take an active and leading role with the help of your specialist team. The main aim of supported self-management is to enable you to develop the skills, knowledge and expertise to:

1. Make positive choices about your health care
2. Manage the physical and emotional impact of a Monoclonal Gammopathy of undetermined significance (MGUS) diagnosis
3. Make long term positive changes to health behaviours (staying active, regular exercise, eating healthy and reducing alcohol consumption)

We know from working with people with other long term medical conditions that supported self-management can improve physical health and well-being.

Your specialist team will discuss supported self-management with you at a point in your care when this option might suit you.

Once this has been agreed with your team, you will no longer have routine follow up telephone appointments. Instead, you will be able to contact your team at The Clatterbridge Cancer Centre directly to arrange a follow up appointment only if you have any concerns.

Your team will also review any blood test results and contact you if they have any concerns.

Online health records

As part of your follow up care you will be provided with secure and confidential access to an online resource called My Medical Record.

This resource can be accessed via the internet, and you can use it to:

- Check your blood results
- Message your specialist team
- Access information on living with MGUS
- Take assessments to monitor issues related to your diagnosis

We understand that not everybody feels comfortable with technology or has access to a computer on a daily basis, so if you choose not to register on My Medical Record you can continue to take assessments and receive information in paper format.

Surveillance

Your specialist team will use surveillance to monitor your condition and progress. This is the same as the current process which is used to ensure any changes are picked up effectively.

As part of your surveillance you will have regular blood tests. The results of these will be available for you to access through My Medical Record and you will also be informed by letter. This letter will also be available on the My Medical Record site.

Occasionally a patient will be asked to go for a repeat blood test or a further investigation. Your specialist team from the Haemato oncology department will organise these tests for you if needed and you may contact your support worker to discuss this further if you have any concerns.

If you do have any concerns about your test results you can contact your support worker by telephone or email. We will contact you directly if we need to discuss your results with you.

Supported self-management workshops

You will be invited to attend a two hour supported self management workshop run by your specialist team and your support worker. The workshop aims to provide you with the skills and confidence to self-monitor your condition and to make the best use of the online My Medical Record system. We will also help you to recognise signs and symptoms to watch out for as well as manage lifestyle changes and set your own goals for staying well. The following will be covered in greater detail:

- Introduction to supported self-management
- My Medical Record training
- Surveillance programme
- Health MOT checklist
- Healthy lifestyles
- Moving forward

Assessment and care planning

You will be asked to complete regular assessments in the form of a Health MOT checklist. You can access this via the online My Medical Record system or in paper format. This checklist is a way of identifying any problems or concerns that you may have. These might include practical issues such as working or dealing with the physical and emotional effects of your condition, or concerns relating to your relationships or family life. The checklist will reflect your individual needs so that we can support you with a clear care or action plan. This can help you to self-manage your care or identify when other help or resources could be useful.

How do I contact my team?

Using the online My Medical Record system you will be able to send an email to your specialist team who will respond within two working days. Email sent at the weekend will be responded to on the next working day. Alternatively, you can call the **Support Worker team on 07899 774701** and leave a voicemail. This number is checked daily and you will be responded to within one working day.

Finding support

You may have already found that people have different ways of living with their condition. There is no right and wrong way, just what works for you. Some people prefer not to talk about it, while others find it helpful to discuss their experience. Your specialist team is there to help you with support. Details about local support groups available are on the My Medical Record system or you can contact your support worker.

Further information & useful contacts

Myeloma UK provides information and support to people affected by myeloma. It helps to improve treatments through research, education and awareness.

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How we produce our information

All of our leaflets are produced by staff at The Clatterbridge Cancer Centre and this information is not sponsored or influenced in any way. Every effort is made to ensure that the information included in this leaflet is accurate and complete and we hope that it will add to any professional advice you have had. All our leaflets are evidence based where appropriate and they are regularly reviewed and updated. If you are concerned about your health in any way, you should consult your healthcare team.

We rely on a number of sources to gather evidence for our information. All of our information is in line with accepted national or international guidelines where possible. Where no guidelines exist, we rely on other reliable sources such as systematic reviews, published clinical trials data or a consensus review of experts. We also use medical textbooks, journals and government publications.

References for this leaflet can be obtained by telephoning 0151 556 5570.

If you need this leaflet in large print, Braille, audio or different language, please call 0151 556 5570.

If you have a comment, concern, compliment or complaint, please call 0151 556 5203.

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