# **Important notice**

If you change your address, GP, or any other personal details, please let us know by contacting the team on;

01744 646796

St Helens Hospital Marshall Cross Road, St Helens, Merseyside, WA9 3DA Telephone: 01744 26633 Whiston Hospital
Warrington Road,
Prescot,
Merseyside,
L35 5DR
Telephone: 0151 426 1600





# Haematology Self-Supported Follow up

Your guide to supported self-management and remote surveillance

This leaflet can be made available in alternative languages / formats on request.

如有需要,本传单可提供其他语言/版式 此單張的其他語言/格式版本可按要求提供 Na żądanie ta ulotka może zostać udostępniona w innych językach/formatach.



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# **Introducing Supported Self-Management**

This booklet aims to explain what Supported Self Management (SSM) is and how it works. It contains all the information you need to self-manage your condition with the support of the team and allows you to keep in touch with us.

Traditionally, patients with a haematology condition such as yours have attended clinic for a face to face review with the team to discuss blood results and any new symptoms.

Although some patients find these appointments useful and reassuring, many find them a source of anxiety.

Face to face appointments often mean a lengthy wait to see a clinician and also result in incurring parking or transport costs.

As your condition is stable you have been selected by your healthcare professional for distance monitoring using Supported Self-Management. This type of follow up allows the team to continue to observe your condition with fewer visits to hospital whilst allowing you to communicate any physical, practical, and emotional or relationship concerns to your Haematology Nurse Specialist or Support Worker.

# **Local Information**

# **Macmillan Information & Support Centre**

Telephone; 01744-647000

### Macmillan national helpline/benefit line:

Telephone; 0808 808 0000

# **Lyndale Cancer Support (Knowsley):**

**Telephone**; 0151 489 3538 www.lyndalecancersupport.co.uk

# **St Helens Cancer Support:**

**Telephone**; 01744 21831 www.sthelenscancersupportgroup.org.uk/contact-us

# **Widnes and Runcorn Cancer Support Group:**

**Telephone**; 0151 423 5730 www.widnesandruncorncancersupport.org.uk

# **Carer Support Knowsley:**

**Telephone**; 0151 549 1412 www.knowsleycarers.co.uk

# **Carer Support St Helens:**

**Telephone**; 01744 675615 www.sthelenscarers.org.uk

# **Carer Support Widnes:**

www.haltoncarers.co.uk

# **National Information continued**

# **Macmillan Cancer Support**

**Telephone**; 0808 808 0000 (Monday to Friday, 9am to 8pm) www.macmillan.org.uk

#### **NHS Carers Direct**

Freephone; 0300 123 1053 (Monday to Friday, 9am to 8pm; Saturday to Sunday, 11am to 4pm) - www.nhs.uk/carersdirect

#### **NHS Choices**

The site includes all NHS online services and information. www.nhs.uk

#### **Carers Trust**

Telephone; 0844 800 4361 - www.carers.org

### **Disability Rights UK**

Offer practical advice for people living with a disability or health condition. They provide access to more than 9,000 public toilets for disabled people in the UK via a Radar NKS Key which can be purchased from the Disability Rights UK online shop. www.disabilityrightsuk.org

#### Turn2us

A UK charity that helps people access money which may be available to them, through welfare benefits grants and other help. Telephone: 0808 802 2000 (Monday to Friday, 9am to 8pm) - www.turn2us.org.uk

# **How it Works**

You will be provided with log in details for Supported Self Management via My Medical Record; this is an online platform where you can access and view your blood results or email us at a time that is convenient for you.

These emails will be picked up during normal working hours by your Haematology Support Worker and responded to as appropriate.

You will receive notifications to attend for blood tests and to complete a health MOT / questionnaire. We will then review these results each time they are performed and communicate the result to both you and your GP. The team will also be able, if needed, to direct you to the most appropriate information or support service that you might require.

Don't worry if you do not have access to an electronic device to view My Medical Record; you are still able to take full advantage of Supported Self-Management.

Your Haematology Support Worker can manage this for you and communicate everything via telephone and post. You may have a relative, carer or close friend who can assist you in accessing My Medical Record.

If you have any concerning symptoms or worries about any aspect of your blood disorder, you can telephone a member of the Haematology Support Team or email us directly using My Medical Record. If deemed necessary, you will be seen urgently by the Haematology Clinical Team at the earliest face to face appointment.

# **Summary**

# **Support:**

- You will have a dedicated Haematology Support Worker who will be your first point of contact for any concerns you have regarding your diagnosis.
- Your Haematology Support Worker can be contacted via phone or email through My Medical Record.
- You will be invited to a workshop session at which information will be provided to equip you with everything you need to know to confidently self manage your follow up pathway and live as healthy and active a lifestyle as possible.

# **Self-management:**

- Remote follow up puts you in control of your care.
- You will be able to check the date of your blood tests,
- Access your test results and contact your Haematology Support Worker at a time that is convenient for you by using the email facility on My Medical Record via your Patient Portal.
- You can flag up concerning symptoms in a timely manner. Evidence suggests that outcomes are better when these symptoms are reported as they happen, rather than waiting until your next routine follow-up appointment.
- You can choose how much or how little you access the Information and support on offer, it will all be made available to you.

# **National Information**

# **Myeloma UK**

Information on myeloma diagnosis, symptoms, causes and treatments

**Tel**; 0131 557 3332 www.myeloma.org.uk

# **Lymphoma Action**

Information and support

**Tel**; 0808 808 5555 www.lymphoma-action.org.uk

### **Cancer Research UK**

Information and details of clinical trials.

Helpline; 0808 800 4040 www.cancerresearchuk.org

#### **Carers UK Carers Line**

Freephone; 0808 808 7777 (Monday to Friday, 10am to 4pm) www.carersuk.org

#### **Citizens Advice Bureau**

www.citizensadvice.org.uk

#### **Dial UK**

Local disability information and advice. **Telephone**; 0808 800 3333 www.dialuk.org.uk