YORKSHIRE & HUMBERSIDE HAEMATOLOGY NETWORK

Newsletter

Issue 2 - 2013

The Yorkshire & Humberside Haematology Network

The Yorkshire & Humberside Haematology Network (YHHN) was set up in 2004 by doctors, nurses and researchers in your area to study blood disorders and the best way to manage them. We contacted you soon after you were diagnosed to ask if you would be willing to receive further information from us and you are receiving this newsletter because you agreed that this would be ok. We hope that it will bring you up-to-date with some of the findings from our work and the activities that have been taking place in the area. YHHN is managed by researchers at the University of York – if you would like more information about this study you can go to our website (www.yhhn.org) or contact us by phone or email – our details are on the back of this leaflet.

Symptoms

We have been sending questionnaires to people with blood disorders in the area since 2004 – you may have completed one yourself. One part of the questionnaire asks about symptoms people had before diagnosis, and so far over 3000 people have told us about their experiences. The following section tells you about some of the findings from this study.

Symptoms or no symptoms?

Overall, 3 out of 10 people told us that they did not have any symptoms at all. These people were often diagnosed after a blood test for another illness or at a routine check-up. The number of people with symptoms was slightly different depending on the type of blood disorder. There is more information about this on the next page.

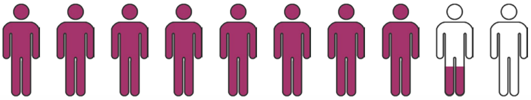
70%

of **all** people who **completed the questionnaire** reported having **symptoms**

87%

of people with **Hodgkin lymphoma** reported having **symptoms**

83%

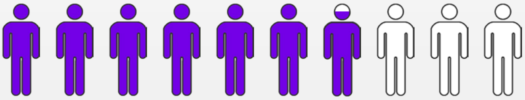


of people with **non-Hodgkin lymphoma** reported having **symptoms**

77%

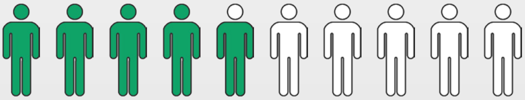
of people with **acute myeloid leukaemia** reported having **symptoms**

69%



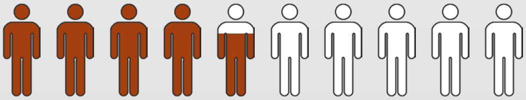
of people with **myeloma** reported having **symptoms**

48%



of people with **myeloproliferative neoplasms** reported having **symptoms**

47%



of people with **chronic lymphocytic leukaemia** reported having **symptoms**

Type of symptoms

The symptoms that people told us about were very varied. The most common symptoms mentioned by people with blood disorders are shown below, as well as some of the other symptoms that were reported less often.

Top 5 symptoms: all blood disorders

30% tiredness

28% pain

26% lump

14% breathing problems

10% skin problems

some other symptoms: all blood disorders

heart problems

dizziness

headache

eye problems

weight loss

Differences by type of blood disorder

The symptoms that you told us about were different depending on the type of blood disorder. The boxes on the next page show the most common symptoms mentioned by people with a selection of different blood disorders, as well as some of the other symptoms that were reported less often.

non-Hodgkin lymphoma (NHL)

top 5 symptoms

- **50%** lump
- **25%** pain
- **21%** tiredness
- **12%** stomach problems
- **11%** breathing problems

some other symptoms

- heart problems
- sweats
- weight loss

Hodgkin lymphoma (HL)

top 5 symptoms

- **57%** lump
- **28%** sweats
- **24%** tiredness
- **21%** skin problems
- **20%** breathing problems

some other symptoms

- pain
- weight loss
- stomach problems

myeloma

top 5 symptoms

- **62%** pain
- **29%** tiredness
- **16%** muscle & joint problems
- **9%** breathing problems
- **7%** infection

some other symptoms

- heart problems
- weight loss
- stomach problems

acute myeloid leukaemia (AML)

top 5 symptoms

56% tiredness

31% bleeding/ bruising

27% breathing problems

22% infection

15% pain

some other symptoms

- fever
- hearing problems
- muscle & joint problems

myeloproliferative neoplasms (MPN)

top 5 symptoms

28% tiredness

25% skin problems

23% pain

13% heart problems

11% headaches

some other symptoms

- dizziness
- bleeding/ bruising
- stomach problems

chronic lymphocytic leukaemia (CLL)

top 5 symptoms

36% tiredness

23% lump

18% infection

13% pain

11% sweats

some other symptoms

- breathing problems
- weight loss
- fever

York Haematology Support Group

Throughout 2012 we have been working closely with Carol Miller who lives in York and was diagnosed with acute myeloid leukaemia in 2004. Carol wanted to set up a support group for people with blood disorders in the area and asked us to help her to do this. Carol has since formed the York Haematology Support Group and our interview with her tells you more about how she did this.

YHHN: Carol, can you tell us why you decided to set up the Haematology Support Group in York?

Carol: I was diagnosed in 2004, and there was no information for patients apart from the information that I got from the medical staff, which wasn't enough for me. I relapsed again in 2006, had a course of chemotherapy, and I would have liked someone to talk to, someone that had been through it and knew what it was like. There wasn't anything available and there weren't any support groups in the area, so I thought, "Right, this is my mission!"

How did you go about setting up the group and who was involved?

Because of confidentiality issues, it was difficult to get in touch with patients to set up the group. I received an invitation to the patient partnership from YHHN and got in touch to ask if you could help me set up the group, which you did. With your help, and with the Cancer Care Centre at York Hospital, I started talking with three other patients who I met at a discussion group meeting, and they helped me to get things going. But we wouldn't have been able to do it without help from YHHN.

Where did you find out about how to run a group?

I went to be an observer at the Stoma Support Group, which has been going for quite some time. I went and saw what they did, what happened, and everything stemmed from there, really. I got ideas for fundraising and things from what they were doing, and then I went my own merry way.

How did you publicise the group?

We had posters dotted around York Hospital, in the clinic. I contacted Leukaemia Care and Myeloma UK and they put it on their websites. The Lymphoma Association have also helped out by publicising us and sending literature. I also advertise in the local press and local magazines that are delivered free to all households in York.

Can you tell us about what happens at the meetings?

Well, it's an informal group and we've just moved to a new venue. We meet once a month and people can just turn up but most people contact me first. We've had guest speakers from the University and Macmillan and we've also had more social meetings. We have a little raffle to try and raise some funds should we need them, and it's just a friendly group - it's just people speaking to other people that have been through the same things.

What's next for the group?

We're hoping to visit the diagnostic labs in Leeds at some point, and we're keen to set up a 'buddying' system - matching newly diagnosed patients with a 'buddy' that's been through the same treatment to help support them.

The York Haematology Support Group meets at their new venue at 7pm on the first Thursday of every month:

Huntington and District Working Mens Club
1 North Moor Road, Huntington
YO32 9QS (ample free parking)

If you would like to attend, or want any information about how to set up your own support group, you can call Carol on 01904 330705 or email: Carol.Miller2@ntlworld.com

The patient partnership

In 2009 we worked alongside patients, relatives, doctors and nurses to set up the YHHN Patient Partnership. Since then, the 600 or so people involved in this group have really helped us in our research – some have taken part in discussion groups or filled in questionnaires about their experiences, and others have advised us about our study paperwork and website. This group is very important to us and we really appreciate the help that we have received over the past years.

We would like to take this opportunity to say a big thank you to anyone who has generously given up their time and shared their experiences with us. With your continued help, we hope to find out as much as we can about blood disorders and make sure that people with these diseases have the best care possible.

coming soon...

the new YHHN website

www.yhhn.org

scan this barcode with your smartphone QR reader to visit the website:

Contact Us

Freephone: 0800 328 0655

Email: enquiries@yhhn.org

Website: www.yhhn.org

LEUKAEMIA & LYMPHOMA RESEARCH
Beating Blood Cancers