

## INFORMATION GIVING – KEEPING PATIENTS AND PROFESSIONALS INFORMED



Providing information is an important element of the care and management of patients generally, but probably most pertinent in the cancer care setting. At a national level, the NHS Cancer Plan (2000, 2002) recommended the access and availability of information to patients and carers. The NMC (2004) stated that confidentiality, resources and accountability are at the heart of information giving. In daily clinical practice the new code (2008) expects nurses to further ensure patients 'understand...the information they want or need to know about their health.' NICE (2003) recommends that information is given by specialists in cancer using effective communication. The role of the clinical nurse specialist is cited, with the objectives of informing, advising, supporting and tailoring information along individual needs throughout the patient pathway.

This provides a basis for the providers including the cancer charity sector. Ken Campbell, Clinical Information Officer, Leukaemia Research said: 'We believe patients should be able to match their information needs to the course of their haematological illness. A major initiative is the development of information prescriptions, which is the

provision of the right information at the right time.'

Leukaemia Research now produces over 40 patient information booklets and factsheets on haematological malignancies and related blood conditions.

'Our booklets provide a high level of clinical information, especially for patients who may be looking for more specific knowledge about their disease. Patients indicate that our literature may be useful well after their initial diagnosis and treatment,' he said.

'One great strength of the charity sector is the ability to act outside formal information frameworks and directly address the needs of patient groups who might otherwise be ill-served. We aim to serve the wider population where regional services may not be able to,' Ken added.

Patients with a haematological malignancy present with difficult and often complicated disease and health professionals will seek information from relevant and reliable sources so they can effectively care for their patients. Livvy Fernandes, *Nursing Leukaemia*, Leukaemia Research, said: 'Nurses are eager to fill their gaps of knowledge about

these serious diseases. Haematology patients tend to be nursed in specialised units so there is limited clinical experience available to many nurses. The *Nursing Leukaemia* campaign continues to aim to direct nurses to relevant sources like our patient information and keep them informed of nursing practice in this area.'

**"My focus when speaking to callers is to give them clear clinical information. Patients, families and friends can be faced with complex diseases in the diagnosis of a blood cancer and therefore require relevant knowledge to understand the nature of their illness, treatment and care. Support services provide patients with a safety net of information in their own home setting."**

Ken Campbell, Clinical Information Officer

Leukaemia Research produces a range of patient information booklets (see [backpage](#) for more details or visit [www.lrf.org.uk/diseases](http://www.lrf.org.uk/diseases)). For more information speak to the clinical information officer on 020 7269 9060.

# MANAGING INFORMATION IN THE HOSPITAL SETTING

From running a student union office to working with heroin addicts in Hong Kong, Tracy Connor chose nursing in her late twenties. She trained at Shotley Bridge Hospital, Newcastle, a district general where, in her final year, she was given the opportunity to work with haematology patients.

Eventually as a senior staff nurse she set up a medical-haematology day unit. She said: 'I have worked in the field ever since. It is a very addictive speciality and once you get a taste for it you are hooked.'

Today she is a Macmillan Haematology CNS based in haematology out patients, Lincoln county hospital, United Lincolnshire Hospitals NHS Trust. One of three CNSs based across the trust, she works independently and has been in her current role for five and half years. 'From my student days my ambition was to be a Macmillan nurse in haematology,' she said. 'It is the best job in the world. Demanding and challenging but never dull, there is always something more to learn and the patients are wonderful.'

## Tailoring information

Lincoln was one of the first locations in the UK to have a Macmillan information centre. One of Tracy's main roles is information provision in haematology. Tracy provides both verbal and written information. This spans from diseases, chemotherapy, side effects and psychological issues to national and local support groups and reputable websites. The department receives at least 100 new patients a year. Tracy has contact with many of these. Furthermore, in haematology progressively more patients live for a long time with their condition, as many are cured. On average she sees 40 patients in a week, and said: 'It was as ward sister that I first began to take a real interest in quality information provision for patients. Giving the right information at the right time is important. I aim not to overload patients. There needs to be a provision of information that is in language they can understand. I don't presume that all patients want information. Whilst information actually reduces anxiety there are some people who just don't want it and it shouldn't be pushed onto them.'

Tracy gives patients an easy-to-carry information package at diagnosis. She said: 'It is tailored to their specific needs and haematological condition. Patients often bring this with them to clinics and add information given at later stages to it to keep it all together. They also have my card.'

'Haematology patients specifically need information around their condition, treatments regarding chemotherapy, transplants, side effects that occur due to treatments, the risk of infection. They also need to know about life beyond their cancer treatment, and lifestyle issues that include financial help,' she said.

Tracy does a lot of face-to-face consultations which she feels is very effective, particularly when reinforced with written information. They also have a large notice board dedicated to patient information near the entrance of the ward. She said: 'We have lots of telephone queries too which sometimes result in sending written information out. I recommend websites and people do email me questions. I don't think you can beat face-to-face interaction. Not all cancer patients have the luxury of this, so the helplines provide invaluable help and support and act as great sign posts.'

## Relevant and reliable

She believes that nurses should be providing accurate and up-to-date, evidence-based information about haematological malignancies because of rapid advances in this speciality. She said: 'Information can quickly go out of date. Also patients often come in and ask about drugs and procedures which they have read about on the internet. We need to maintain the trust and respect of our patients by staying current and relevant.'

Tracy uses specific information for haematology patients and is always looking to see what's new in the field. Her unit is



currently reviewing the new information from Leukaemia Research on neutropenia with a view to utilising it in outpatients. Existing resources include *Donating Stem Cells* and *Seven Steps*, by Leukaemia Research for those undergoing donor transplants and information about stem cell transplants from Macmillan Cancer Care (Backup) and Myeloma UK.

Her future aims are to be able to measure the success of information giving. She said: 'Some of the other site-specific nurses have been involved in information prescriptions along with the other trusts in our network. I am sure it is something we will be considering in haematology.'

Information can be daunting to patients. Tracy said: 'Giving information can be a minefield, particularly when first diagnosed. To most people the vocabulary of conditions and treatment is totally new, so as well as being acutely anxious, even when explaining things in simple language, misunderstandings can occur. Fortunately it doesn't happen very often and is usually over issues that aren't life threatening.'

Ultimately, Tracy feels giving appropriate and informative resources to help patients understand their disease is very rewarding. She said: 'It's satisfying to see people go from being frightened and powerless by their diagnosis to gaining control and being able to cope which good, timely information facilitates. I enjoy communicating with people, that's what this job is all about to me – that's what gives me the most satisfaction.'

## Don't miss out!

Nurses who newly register for the *Nursing Leukaemia* pack may find that they don't have the full set of news magazines. If you would like to access back issue copies of the magazine these can be downloaded from the *Nursing Leukaemia* website at [www.nursing-leukaemia.org.uk](http://www.nursing-leukaemia.org.uk)

# A SPACE FOR INFORMING – THE NURSE-PATIENT CONSULTATION



Maggie's Centres are resource centres for cancer patients to get face-to-face advice and support. A recently opened building at Imperial College Healthcare NHS Trust marks the sixth venue for Maggie's intended purpose of providing a location for every patient to access support around the country.

Established centres in Scotland and Oxford have already proved that patients and their relatives value an informal and independent point of support during or after treatment. Set up by the legacy of Maggie Keswick Jenks, an architect who died of breast cancer in 1995, the centres place environment as an influential factor in the cancer patient's experience.

Maggie's Centres have been pivotal on an intermediary focus for information giving. The centre programmes are evidence based and are aimed at enabling patients and their relatives to feel they can manage their cancer experience. There are face-to-face consultations as well as group activities. Centres offer a combination programme of support which include sessions on yoga, relaxation and visualisation, nutrition workshops, Tai chi and stress management.

## Highlands centre

Scotland has five established Maggie's Cancer Centres. Debbie Davies is an information and support specialist, and works at the Maggie's Highlands centre located at nearby Raigmore Hospital, a district general in Inverness, with an oncology and haematology cancer centre.

Debbie originally trained as a Macmillan nurse and is a member of a team which includes a clinical psychiatrist and volunteer who each day meet and greet visitors. The centre opened three years ago.

Highlands has up to 30 visitors per day for all cancers. Between January to March this year, they had 66 visitors for haematology based enquiries. Debbie said: 'We see patients or relatives who are affected by a family member's malignancy. These diseases create a major impact on quality of life, diet and their financial life. We help them to gather information to meet their individual needs whether it is about bone marrow transplant or chemotherapy options.'

There is a non-specific referral process and patients remain independent while still being treated alongside conventional routes. Support groups can meet at Highlands once a month. She said: 'Relatives want to get an understanding of the diagnosis. This includes information about biological effects, how bone marrow works, why chemotherapy produces hair loss. We help them to support patients.'

The rural location means some patients will find it difficult to travel to the site. Patients may have to be transferred from Raigmore to other specialist haematology centres for more complex treatments. Others may find they have to travel to Raigmore from the Western Isles and Orkney. All of this has the impact of large distances, like journey times, so email and an advice line offer alternatives.

Maggie's at Fife opened in November 2006. Unlike many Maggie's, it is not located in the vicinity of a major cancer centre and lies on the site of Victoria Hospital, a DGH, with one haematology unit.

## Fife centre

Lorna McGoldrick, Information Support Specialist at Fife, has worked there for 18 months. Maggie's nurses have a dual role providing information support whilst

managing therapeutics according to the centre's programme. She spent eight years at the frontline of haematology at the Royal Infirmary in Edinburgh and also worked for stem cell transplantation at the centralised oncology centre at Western General Hospital in the City.

A two-nurse team at Fife also includes a benefit advisor specialist. Visitors are directed via a GP referral, staff on the ward where they are being treated or via the local media.

The Fife centre tends to see people with myeloma, chronic leukaemias and lymphomas. Acute leukaemias tend to be managed in hospital. Patients undergoing frequent treatments for haematological malignancies may be physically compromised. Lorna said: 'When patients have a low immunity they need support mechanisms to help maintain their general physical status. The Maggie's programme takes several approaches to look at their treatment, diet, lifestyle and wellbeing.'

The Maggie's care team will not intervene in treatment issues, but if patients are concerned about areas of their treatment, they will encourage them to see their oncologist or nurse specialist. She said: 'Seeing people flourish with tailored information and support is heartening. Also people having a place to ask the difficult, perceived foolish questions, like what does a lymph node look like? We make it possible to give people the support and space to gather their thoughts, face their fears and access the resources they have within themselves for a fuller life. Or as Maggie Keswick Jenks said: "Not to lose the joy of living in the fear of dying."'

For more information about Maggie's see [www.maggiescentres.org](http://www.maggiescentres.org)

# HELPLINE NURSES AND ADVISORS — PROVIDING INFORMATION ACROSS ADVICE LINES

**“Working on the CARE Line brings immense personal satisfaction and calls can be both inspiring and humbling. Each caller is unique and it is a privilege to be allowed to share an emotional confidence. Hearing that the call has made a difference is very rewarding.”**

A Leukaemia CARE Line Advisor

Leukaemia CARE’s CARE Line is a dedicated freephone telephone service on 0800 169 6680 for anybody affected by leukaemia, lymphoma, myeloma and the allied blood disorders. It is available and fully staffed 24 hours a day, seven days a week. The line can offer support, advice and information. Help includes: information on diet, fatigue, hair loss etc including booklets; financial advice, welfare and benefits; alternative treatments; travel insurance details; and palliative care and/or bereavement.

Patients can also call the CARE Line free from a mobile on 0808 801 0444

Registered charity no. 259483, Scottish registered charity no. SC039207

**“When people say thank you for helping them, it is so rewarding and makes it all worthwhile. That’s what I love about the work we do at the Association.”**

Anne Taylor, Patient Support Officer

The Lymphoma Association has seven Patient Support Officers (PSOs). They take over 300 calls a month about lymphatic cancer, from patients, family members or a friend. They provide over 100 different publications, both supportive and covering topics such as fertility, hair loss and treatment types.

PSOs send callers a general information pack, containing the Association’s newsletter, contact card and magazine. To avoid too much information, the helpline staff only send out information specific to callers’ needs.

Tel no: 0808 808 5555

Website: [www.lymphoma.org.uk/support](http://www.lymphoma.org.uk/support)

Registered charity no. 1068395

**“Infoline callers can be very distressed and it takes great courage to make the call. By providing answers and support, I am able to help patients take control of their disease and reduce their personal anxiety. Often friends, families and carers call to ask important questions, to clarify discussions with healthcare professionals or simply for the chance to anonymously express their distress and concerns. The infoline support is incredibly worthwhile and a satisfying job.”**

Ellen Watters, Myeloma Information Nurse Specialist

The Myeloma UK Infoline is staffed by two Myeloma Information Nurse Specialists. It is a freephone service available 9am-5pm Monday to Friday and provides people affected by myeloma with practical advice and emotional support while listening to callers’ concerns.

The Infoline receives around 400 calls per month. Caller enquiries relate to myeloma, treatment options and the psychological impact of the disease.

Myeloma UK: Tel no: 0800 980 3332 or email [askthenurse@myeloma.org.uk](mailto:askthenurse@myeloma.org.uk)

Website: [www.myeloma.org.uk](http://www.myeloma.org.uk)

Registered charity no. SC026116

**“When people are living with cancer, it can be very daunting. Often they are trying to understand new medical terms, think about practical everyday issues like work and money, and deal with the complex emotions cancer can bring. Our helpline information includes the latest drug trials, questions about chemotherapy or radiotherapy including side effects, practical help and advice.”**

Alison Boyd, Cancer Information Nurse Specialist

Macmillan Cancer Support has merged with Cancerbackup. Last year they answered 39,524 calls and emails and continue to produce Cancerbackup’s high-quality information.

General information freephone Macmillan CancerLine on 0808 808 2020

Cancer Information Nurse Specialists freephone: 0808 800 1234

Publications will soon be available free of charge to health and social care professionals as well as to patients and their families. Current orders at [www.cancerbackup.org.uk](http://www.cancerbackup.org.uk) or [www.macmillan.org.uk](http://www.macmillan.org.uk)  
Registered charity no. 261017

**“Users find it easier to talk to someone anonymously, especially about difficult issues. Also many of the relatives and friends may not have easy access to their loved one’s healthcare team, or may want to discuss issues privately with someone who is impartial and anonymous.”**

Martin Ledwick, Head Cancer Information Nurse

**“I enjoy the challenge of using my existing skills and knowledge in a completely different setting. Additional time with a helpline nurse, can be very supportive. Most of all I love having time to talk to people and listen to their concerns, which is what this job is all about.”**

Jean Slocombe, Cancer Information Nurse, CRUK

The Cancer Research UK (CRUK) information team comprise of nine nurses. Last year, the information team answered over 10,000 enquiries ranging across all cancers. Call 0808 800 4040  
Website: [www.cancerresearchuk.org.uk](http://www.cancerresearchuk.org.uk)  
Registered charity no. 1089464

# BEAT THIS!

The challenges of caring for patients with a haematological malignancy stretch from hospital to the community. Christine Morris, is nurse lead for the community children's nursing team in Crawley, West Sussex. The team work over a wide regional area covering Crawley, Horsham and East Grinstead. She said: 'It's a very privileged job where strangers invite you into their homes and make you welcome at a time of their life when they have a sick child and often would rather be left alone.'

Earlier this year, Christine heard about the Run To The Beat half marathon on the radio and decided to run in October for Leukaemia Research. She said: 'I thought that running to music would be great. I think that music encourages people to support the runners, which is important to me when running long distances.'

She has completed many runs including the ING New York City marathon. She said: 'I began running because I developed high blood pressure and knew I needed to take up some form of regular exercise. I am lucky enough to live near the Worth Way, a picturesque run along the old disused railway track from Crawley to East Grinstead. The course in October seemed quite flat, which suited me. I did not get a place for the Flora London Marathon this year and



taking part in London's Run To The Beat was a shorter alternative'.

While Christine was working hard to get friends and family to support her events, she looked forward to taking part, and said: 'I love the atmosphere of events and think it enthruses you to do well. I love meeting others and the camaraderie of an event like this is difficult to explain to others. It is not the speed that counts but the taking part.'

Children with cancer, leukaemia or other haematological diseases form a high percentage of Christine's nursing team workload. 'I like the contact with children, young people and families best. We see children and young people with leukaemia with their family at least once a week for up to

three years. So at the end of their treatment we will know them very well and will have been with them through some of the highs and lows of treatment,' she said.

Christine sees about five newly diagnosed children with leukaemia each year in her area, and said: 'This adds impact to our oncology case load. More importantly, not all children go through treatment successfully. I would like to think that our input can help these families at this time.'

If you would like to enter a future running event for Leukaemia Research call 020 7269 9001 or email: [running@lrf.org.uk](mailto:running@lrf.org.uk) There are many other triathlon, cycling and walking events up and down the country. Visit [www.lrf.org.uk/sports](http://www.lrf.org.uk/sports) for more information.

## King's Transplant Team celebrate 1,000 transplants

In June, King's marked its 1,000th transplant with a day of celebration. The day's events were sponsored by Leukaemia Research and the Elimination of Leukaemia Fund (ELF) and brought physicians, nurses, patient groups and charities together.

The transplant programme started in 1986 and King's is now the largest adult allogeneic centre in the UK and one of the largest in the world for unrelated transplantation. A key strength of the programme at King's is the integration of research and clinical care to lead in the development of new treatments. As a result King's took a leading role in the development of reduced intensity transplantation and has the largest adult cord programme in the UK.

Michelle Kenyon, BMT Co-ordinator, at King's said: 'The dynamic and continuous changes in transplantation have needed a dynamic and responsive team. The contribution of inpatient and outpatient nursing teams in the delivery of such a wide-ranging portfolio of treatments needs extensive knowledge, good communication skills and the ability to provide excellent patient care.' As Michelle pointed out, these aspects are deeply valued by transplant patients. 'The high point of our 1,000th transplant celebrations was the transplant experience shared by two of our patients — a reminder, if any were needed, of the importance of these treatments and also the value of nursing care in this setting,' she added.

- Leukaemia Research currently invests over £800,000 on scientific research in haematological medicine at King's College.

### About Leukaemia Research

Leukaemia Research commits over £20 million annually to universities, medical schools and teaching hospitals throughout the UK for research into cancers of the blood.

Our research has four main goals:

- ➔ To discover the cause of leukaemia and related cancers
- ➔ To understand how blood cells become cancerous
- ➔ To continually refine diagnostic methods for the rapid and accurate assessment of disease
- ➔ To devise new treatments for the cancers of the blood.

Leukaemia Research is the only national charity dedicated exclusively to improving treatments, finding cures and learning how to prevent leukaemia, Hodgkin's and other lymphomas, myeloma and related blood disorders (myelodysplasia, aplastic anaemia and the myeloproliferative disorders). 24,500 people are diagnosed with a blood cancer in the UK every year.

# HAEMATOLOGY NURSE APPOINTMENT

Jane Gray, Senior Haematology Research Nurse, has recently joined the Division of Cancer Studies at the University of Birmingham. Jane will be working with the early drug development team based within the Centre for Clinical Haematology. Jane trained at the Manor Hospital in Walsall, qualifying in 1993. After working in the hospital environment for five years, she said: 'I got a job as a community district nurse which I loved. I valued the experience it gave me, but missed the hospital life.'

After two years she decided to see if there were any opportunities within her regional trust and saw a post for a haematology staff nurse at the Queen Elizabeth Hospital, for which she applied and was appointed. She said: 'I enjoyed all aspects of my role as a BMT Co-ordinator. It's very different to hands-on nursing and requires you to be very organised and able to prioritise your workload. I also enjoyed working independently, although you are still very much a part of a haematology

nurse specialist team. I think my community experience was invaluable for enabling me to deal with that.'

She sees haemato-oncology patients in phase I/II associated research in bone marrow transplantation, haematological malignancies and adoptive immunotherapy. Jane manages the co-ordination and data management of clinical trials alongside the administration of novel cytotoxic agents. She said: 'The main aims for my new role are to continue the fantastic work the haematology research team have done so far and to help facilitate the recruitment of patients into clinical trials.'

She added: 'The majority of the trials I will be working on involve patients undergoing transplant, so my previous knowledge and experience will enable me to better support them. Also I have found that when I go in to speak to patients about the trials it always leads to general questions about the transplant, so I can answer these as well, rather than having to refer them to someone else.'



- Jane Gray is a contributing author to Leukaemia Research patient booklets including *Undergoing High Dose Therapy and Autologous Stem Cell Transplant*. Jane is led by Professor Paul Moss at the University of Birmingham in a Leukaemia Research part-funded project.

## Diary dates

**4 October 2008**

**Leukaemia Research Open Day, the Royal Free Hospital, London.**

LR scientists are looking at various strategies to cure leukaemias and lymphomas including mobilising the immune system and using gene therapy.

**25 October 2008**

**Leukaemia Research Open Day at the Gartnavel Hospital, Glasgow.**

Find out about research into the root cause of chronic myeloid leukaemia and more.

Both open days are available to the public, nurses and allied health staff. Come and speak to the scientists in laboratory demonstrations. Registration and lunch is free. Call Tilly Sims on 020 7405 0101.

**13 November 2008**

**Transplantation in Haemato-Oncology, Christie Hospital, Manchester.**

A study day for nurses working in transplantation. Watch out for the *Nursing Leukaemia* stand with Leukaemia Research publications. For programme details and registration call Ruth Clout on 0161 446 3925.

## New booklets

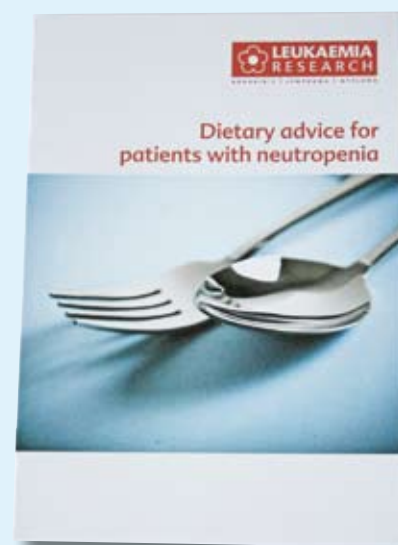
- *Neutropenia*
- *Undergoing Stem Cell Transplant*
- *Chronic Myeloid Leukaemia* – new edition

### Neutropenia booklet

Low numbers of neutrophils (neutropenia) in the circulation due to leukaemia and chemotherapy may place patients at risk of food poisoning. Damage to the gut due to chemotherapy and radiotherapy can further increase infections. The nutritional needs of patients are discussed in a new booklet by Leukaemia Research, *Dietary Advice for Patients with Neutropenia*.

Nurses may find patients with neutropenia difficult to manage. Challenges occur in helping patients maintain a healthy appetite for food intake at a time when they are most vulnerable. Written by the London Haematology Dieticians Group, *Dietary Advice* will be a useful tool in enabling nurses to recognise when a patient is neutropenic as well as how to handle food stuffs. There is also a useful table of food recommendations and suggestions for patients and nurses.

To order further copies, please call the information team on 020 7405 0101 or download copies from [lrf.org.uk/diseases](http://lrf.org.uk/diseases)



To find out more information, contact Livvy Fernandes, Nursing Leukaemia Co-ordinator by:

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- 🌐 Online **[www.nursing-leukaemia.org.uk](http://www.nursing-leukaemia.org.uk)**
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