

Your Patients & Clinical Trials



What happens when patients enter clinical trials?

Nurses are frequently caring for patients who are helping to make new treatments successful during their stay in hospital. The process of clinical trials can be an uncharted area for many nurses.

The *Clinical Trials* booklet by Leukaemia Research takes health professionals along the route of testing new therapies by mapping out the three phases — I, II and III — of scientific trials. It explains the effectiveness of randomised trials, the advantage of being entered into a trial and what patients can expect.

Nurses will find the booklet particularly useful in helping patients to understand potential trial outcomes. Helping patients to better treatments in the course of their diagnosis can throw up many questions. Hopefully, alongside patient consultations, this informative publication will bring reassuring responses for health professionals.

To obtain a free copy of the booklet, call the Information Team on 020 7405 0101 or email info@lrf.org.uk

Read and respond

We have over 18 patient information booklets and other factsheets which we know you have used in your daily working lives. We have plans to produce even more, but would like to know how useful you have found our publications. So whether it's the *Leukaemia Related & Diseases or Bone Marrow & Peripheral Blood Stem Cell Transplantation* booklet, tell us how and why Leukaemia Research publications were useful to you. Email comments to nursing@lrf.org.uk

Nursing with numbers

- There are around 24,500 newly-diagnosed cases of leukaemia, lymphoma, myeloma and related blood disorders in the UK every year
- 111,000 people in the UK are living with leukaemia, lymphoma, myeloma or a related blood disorder
- Leukaemia and lymphoma account for about half of all childhood cancers
- Leukaemia and lymphoma together are the most common cause of cancer death in people aged 1-34
- One in 25 people will develop a blood cancer in their lifetime
- Each day more than 65 people are diagnosed with a blood cancer or related disorder
- 6% of cancers are cancers of the blood — leukaemia, lymphoma, myeloma

Want to find out more?

Open Days are special events which let you learn more about the work of Leukaemia Research. Scientists, doctors and an increasing number of nurses all over the country are working hard to find treatments for these serious diseases.



This is your chance to see the latest developments in drug therapies, while hearing directly from the scientists involved. Scientific advances are allowing them to explore better diagnostic methods, treatments and potential cures for your patients.

Nurses are invited to two public Open Days in:

Newcastle. Saturday 9th October 2004 at the Paul O'Gorman Building, Northern Institute for Cancer Research, University of Newcastle. Attend either morning or afternoon session

Sheffield. Saturday 16th October 2004 at the Royal Hallamshire Hospital, University of Sheffield Medical School. Attend either morning or afternoon session

To register free email Lee on lthompson@lrf.org.uk

About Leukaemia Research

Leukaemia Research commits over £20million 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 devoted 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 diagnosed in 24,500 people in Britain every year.

Nursing Leukaemia 2004 Events Diary

Hot on our heels? We have been. This year *Nursing Leukaemia* has been to over 10 major nursing events and some smaller group meetings.

February 11th
EBMT(UK). 68 delegates.

February 18th
'How to Support the Children of Patients With Cancer' at the School of Cancer Nursing & Rehabilitation: The Royal Marsden Hospital. 45 delegates.

April 19th-20th
British Society for Haematology at Cardiff International Arena. 1,100 delegates.

April 23-24th
Leukaemia Research Annual Conference at the Tower Thistle Hotel, London

May 9-12th
Royal College of Nursing Congress. 5000 delegates

May 20th
North West Haematology Group Meeting. Bury. Plus special presentation by Leukaemia Research's Katy Knight, Research Nurse for CML. 50 delegates.

June 14th-18th
Advanced Haematology Nursing Annual Conference at Hammersmith Hospital. Plus presentation by Leukaemia Research's Ken Campbell, Information Officer.

June 16th
'A Patients' Journey with CLL, in Bury. 50 delegates

June 23th-24th
RCN Haematology & BMT Forum and RCN Blood Transfusion Forum Joint Conference at the Holiday Inn, Birmingham. 250 delegates.

July 7th-8th
Cancer Nursing and Rehabilitation. 200 delegates.

Visit *Nursing Leukaemia* at www.nursing-leukaemia.org.uk to find out where we will be next



Media Resources Centre: Cardiff & Vale NHS Trust

Haematology Nurse Appointments

Two new haematology nurse roles at the University Hospital of Wales, Cardiff have recently been confirmed. Alsya Hayes becomes clinical nurse specialist for myeloma and lymphoma; and Mary Harness becomes Macmillan clinical nurse specialist for myeloid malignancies. Tell us about new haematology specialist nurse roles in your area. Contact nursing@lrf.org.uk

Nurses — how to sign up with us!



Nurses all over the country are signing up to our campaign to receive information, news, events and much more. When you join you receive a free quarterly pack which includes an informative newsletter, events, recent publications and campaign pin badge, notepad and pen. Tell your nurse colleagues to sign up online at www.nursing-leukaemia.org.uk, by postcard or call *Nursing Leukaemia* on 020 7405 0101.

NURSING LEUKAEMIA *news*

Information for nurses

No.1 2004

Nurses to lead in patient information

Welcome! To the first edition of the *Nursing Leukaemia* newsletter. We hope you enjoy reading about our work, where we have been and who we have met along the way.

As the charity for leukaemia and blood cancers, Leukaemia Research recognises that nurses appreciate good evidence based information for their patients. The *NHS Cancer Plan* (DoH 2000) and the recent *NICE Improved Outcomes Guidance for Haematology Malignancies* (October 2003) has given the nursing profession a major role to improve and maintain information giving to patients with haematological malignancies. Our nursing campaign aims to help nurses with this important task.

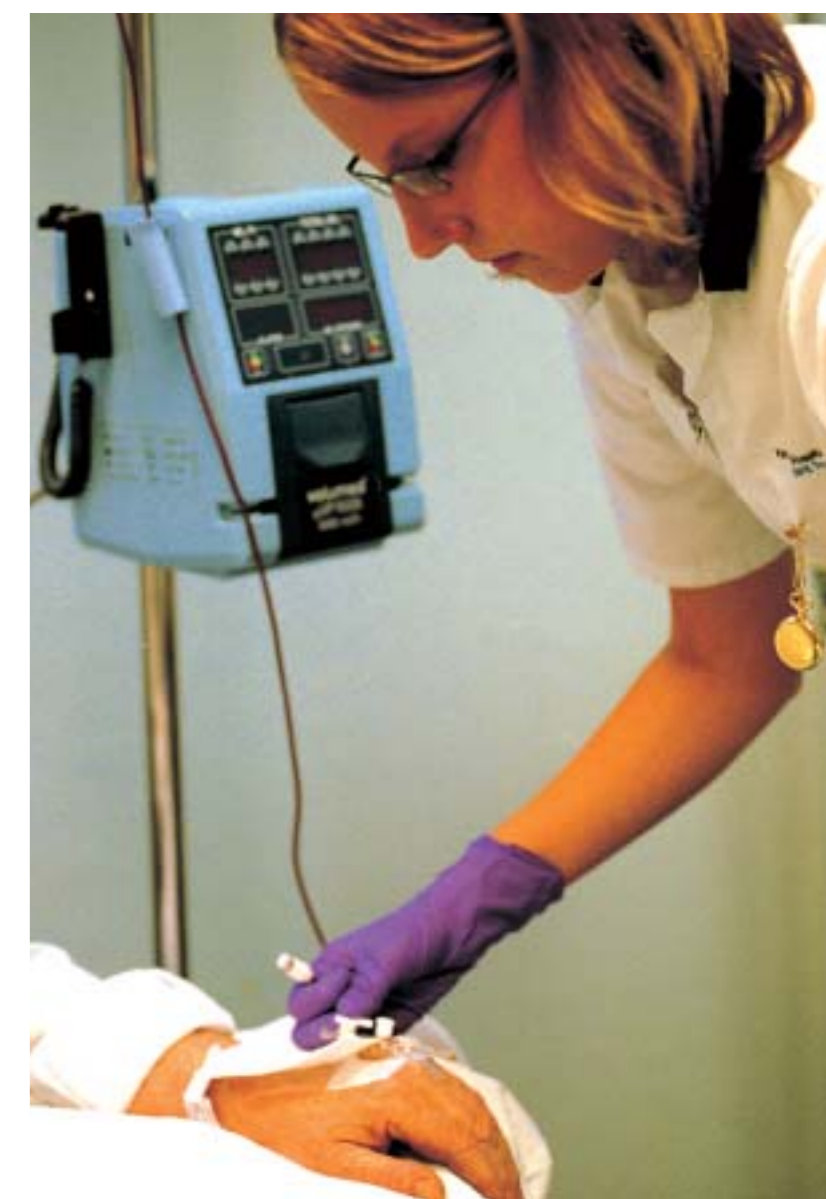
One of the most successful venues for picking up our information is at nurse conferences. We have been to several this year, including those organised by the Royal College of Nursing, EBMT(UK) and the British Society of Haematology. You've told us about what nurses working in haematology need in their daily communications with patients. Marvelle Brown, Assistant Subject of Nursing/Macmillan Senior Lecturer (Haematology) at Thames Valley University, tells us why it is crucial for nurses to keep patients informed from diagnosis to treatment and follow up (overleaf).

Attending major nurse-led conferences and smaller group meetings, we've learnt that our information booklets are an important part of caring for haematology patients. If you attend a major conference, we hope that you will be able to speak to a *Nursing Leukaemia* representative to discuss your information needs. Many of you have also found our publications useful in your personal study, so please keep reading.

Whether it is in clinical practice or scientific research, your nursing skills are being recognised. So to support your patient information, we will bring you some innovative nurse-led stories.

Our web pages devoted to nurses can be found at www.nursing-leukaemia.org.uk and used in combination with this quarterly pack, patient information booklets and factsheets, will be an all-round resource. We hope that you will continue to read our publications.

Livvy Fernandes, Nursing Leukaemia Co-ordinator
Leukaemia Research



Where we'll be next

Make Thursday 18th November 2004 a date with *Nursing Leukaemia*. Visit our stand at the RCN Cancer Nursing Forum Conference and Exhibition: 'Is the Cancer Plan Making a Difference' in York. For more details about the conference call Vickey Langley at the Royal College of Nursing on 020 7647 3579

Marvelle Brown, Assistant Subject of Nursing/Macmillan Senior Lecturer (Haematology), highlights the NICE paper in providing services for haematology patients

The NICE guidance on haematological cancer was published in October 2003. Its aim is to ensure effective, competent and consistent practice for managing patients with a haematological cancer.

Haematological cancers as a group make up the 5th commonest of all cancers and are increasing in incidence (Quinn, 2000). It is therefore vital that nurses continue to enhance and develop their skills, competencies and knowledge in providing optimum quality care.

The guidance has six key recommendations (Table 1). From the nine-chapter document, Chapter 2: 'Patient-centred Care', will be the most significant for nurses and focuses on 12 areas (Table 2).

Pivotal to this is the multi-dimensional role of the Clinical Nurse Specialist (CNS) for Haematology within the multidisciplinary team (MDT). The CNS will have greater management of information giving for patients and their carer's about treatment, liaising with health and social services as required. The CNS will need extensive knowledge about the pathology as well as treatment regimes in order to explain to patients, for example, why in some types of haematological cancers (e.g. chronic lymphatic leukaemia) no immediate treatment may be necessary if the patient is asymptomatic.

Patients will receive a lot of verbal information and this should be matched with consistent, high quality written patient information, enabling them to review their knowledge. Likewise, they need time to assimilate the information in order to ask questions.

The NSH Cancer Plan (2000) for England and Wales emphasises good communication between health care professionals and patients. This is essential, both for the delivery of high quality care and for empowering patients. In other words:

INFORMATION given at the RIGHT time in the RIGHT way enables patients to make INFORMED decisions which are RIGHT for them.

Investigating blood cancers and leukaemia has traditionally been the activity of scientists. Nurses are now proving to be strong team members in the battle to fight these serious diseases

Julie Arrazi was the first haematology trained nurse to be funded by Leukaemia Research as part of a scientific team investigating leukaemia and blood cancers. She became interested in haematology whilst working in orthopaedics and went from 'bone-to-bone-marrow'.

"My flatmate worked as a haematology nurse and made the work sound exciting, challenging and rewarding with nurses building up close relationships with patients," Julie said. "People with leukaemia often receive frequent treatment with sometimes intensive therapy. This requires prolonged close observation and monitoring throughout their diagnosis, treatment and follow up. I really enjoyed getting to know my patients whilst helping them through a particularly difficult time in their lives," she added.

Julie has spent well over a decade in oncology and haematology nursing in several different regions of the country. She started her career as an E-grade staff nurse in Oxford working with the ICRF (Imperial Cancer Research Fund). During the nineties, she worked in Bone Marrow Transplantation (BMT) in London's Charing Cross Hospital, the Cheltenham Hospital in Gloucester and then finally at the BMT unit in Birmingham.

Treatment dilemma

In 2002 Julie was offered the post as trials sister for a Leukaemia Research project to improve the positive effects of bone marrow transplant in patients who experience the graft versus leukaemia (GvL) effect. Lead by Professor Paul Moss, at the Institute of Cancer Studies in Birmingham, the study is currently at the pre clinical stage of the trials process.

At present there are limited options for patients when they relapse after an allograft transplant. Donor lymphocyte infusions are effective for patients who have chronic myeloid leukaemia because of the graft versus leukaemia effect.

Using donor lymphocytes too soon after the transplant is associated with the debilitating graft versus host disease.



Julie sees patients regularly in her role as trials sister

Julie explained: "The new donor immune system recognises the patient's skin, gut, liver and haematopoietic cells as foreign and mounts an inflammatory reaction. Graft versus host disease, or GvHD, can vary from a mild skin rash to skin desquamation, severe diarrhoea and life threatening liver failure. Changes like these can make nursing management of this disease difficult, as well as impede the patient's recovery following a transplant."

Research has shown that the donor immune system can also recognise residual host malignant cells and kill them — this is called graft versus leukaemia response, which scientists are studying. Julie said: "Patients are on strong immune suppressants to prevent GvHD in the early days, with close nursing observation. These are gradually weaned off over a

period of months as the donor and host immune systems become tolerant of each other. The challenge in transplantation is to disassociate GvHD from GvL."

Nursing skills

The main aim of the project is to isolate and treat patients with donor cells that are specifically cytotoxic to the patients' leukaemia cells. "As the cells infused into the patient would be selected to kill only leukaemic cells, the risk of graft host disease would be limited," Julie said. "Most patients who relapse after transplantation do so within a year, when treating with donor lymphocytes is particularly contraindicated. Being able to give specific cytotoxic T-lymphocytes in early relapse would enable more patients the chance of a cure," she added.

Much of Julie's time uses her skills and experience gained in clinical practice. She obtains consent for patient entry to the study trial, gains consent for and undertakes skin biopsies and blood samplings as well as preparing them for the expected study. During the study she manages them when they give blood at two-week intervals, and may take extra blood samples if they have graft versus host disease.

Ultimately, her nursing expertise ensures patients are managed so that the trials process is safe and effective. With the team soon hoping to start treating patients in the early phase of clinical trials, she said: "Most patients are very happy to enter the study. They feel that treatment they have received is due to past research and are glad to help future patients. Moving to better treatment options benefits both patients and staff. Relapse is often more distressing than the original diagnosis. To be able to offer treatment which is safe and effective, helps to ease the situation for all concerned."



Sleep deprivation is one of the commonest experiences faced by patients in hospital. Camilla Ward, Bone Marrow Transplant Nurse Practitioner, Addenbrookes Hospital, was eager to find out whether patients undergoing bone marrow transplantation (BMT) experienced sleep deprivation and what effect this had on patients during and after the procedure.

Camilla Ward has worked in haematology for five years. Whilst working as an E-grade staff nurse caring for patients undergoing transplantation, she recalls: "It was often those that were most unwell that required the most nursing interventions. These patients seemed to have the least sleep."

It was because of this anecdotal evidence that she decided to undertake an MSc in Nursing Research in 2002, to study the sleep patterns of patients on the BMT Unit at Addenbrookes. The nursing and medical literature shows that there are huge consequences from sleep deprivation. Camilla wanted to find out if this was something that patients experienced during their bone marrow transplant.

Her study had a sample of seven patients who were admitted to hospital for 4-6 weeks. She used a combination of research tools which included interviews, sleep diaries and questionnaires. Camilla assessed patients for the study and asked them to start recording their experiences in the sleep diaries for a week, a month before admission and then throughout the whole of their hospital stay.

Patients have different reasons for not being able to sleep. Noise, anxiety, light and treatment interventions can contribute to sleep deprivation. Here some patients say how they felt during their stay in hospital:

"...most nights I doubt whether I ever slept more than two hour at a time — actually slept. I would go back to sleep, but I would see most of the hours of the clock." (Patient comment)

"I definitely slept worse in hospital than I did at home." (Patient comment)

"I could never sleep while I was on the infusion. I did sleep ... but I would always be waking up and then I would look at it and I would think — how much longer? Then they would come in and say 'I am just going to put a flush up' and I would just think — I can't bear it ... I felt like throwing it out the window." (Patient comment)

Outcomes

Camilla found that most patients experienced a distinct change to their sleep pattern during their transplant, for example their sleep was more disturbed, they slept for shorter periods, and the quality of their sleep was reduced. This sleep deprivation was partly caused by the transplantation process and how it affects the body. Frequent nocturnal visits to the toilet and nurses attending patients also played a big part in the disturbances, (although it was not possible to identify how many of the nurses disturbances were necessary). Additionally, noise and light on the ward was also a factor. Even so it was interesting that the majority of patients coped well with this situation and it did not affect them greatly.

Camilla feels that nurses have a crucial role to play in promoting patients sleep during their transplant. "Nurses are in an ideal position to be able to assist patients to sleep well in hospital." This can be achieved by coordinating their treatment to ensure longer periods of undisturbed sleep and by making the ward environment more conducive to sleep. She adds: "Of course it is essential to consider the patients medical condition and their most important nursing needs".

She feels that ... "a few small changes and a bit more forethought can greatly improve our patients sleep during their transplant"

She suggests:

- Sleep promotion to be given a higher priority.
- The use of a brief daily sleep assessment to ensure any problems do not go unidentified.
- To advise patients during key times in their treatment where rest periods will be beneficial to them.
- Minimise nocturnal visits to the toilet by avoiding unnecessary infusions overnight.
- Assess the ward environment looking at sources of noise and light. Aim to reduce this by planning necessary activities around sleep times and at an individual level.

Camilla's study was approved by the Hospital Ethics Committee at Addenbrookes Hospital; her course was funded by the Florence Nightingale Foundation. She presented it at the EBMT Meeting Nurses Forum last year and is currently seeking a study review for publication. For more details about the study contact her at camilla.ward@addenbrookes.nhs.uk