

# Nurse goes bananas

Specialist nurses continue to show their support for research into haematological malignancies in more ways than one. **Aberdeen nurse, Raymond Grieve, ran his first Edinburgh marathon this year and raised an amazing £1,415 donated to Leukaemia Research.**

Raymond has worked in haematology as a staff nurse for four years, and said: 'I first became interested in haematology when I did a placement in a palliative care setting as a student nurse, looking after both haematology and oncology patients. An opportunity arose several years later and I decided to focus my nursing skills on looking after patients within haematology.'

'I'm enjoying it very much,' he added. 'There are a fantastic group of people who work in the haematology department in Aberdeen, particularly within the nursing team. I see the devastating effects of blood cancers first hand and I am also aware of the fantastic work done by Leukaemia Research.'

'I really feel strongly about supporting Leukaemia Research. Their information booklets also help us in our daily work on the ward. It's nice to give something back.'

Raymond ran his marathon with the charity's Banana Army. He managed to complete his marathon in four hours and 51 minutes, and said: 'I was very pleased with

my time as it was very hot on the day — 23 centigrade, much warmer than during my training runs. The last three miles were very tough, but it was well worth it.'



Raymond's work as a haematology nurse led him to run for Leukaemia Research

## Join the Banana Army

The Banana Army is the nickname for Leukaemia Research's running and triathlon team, which last year raised £1.7 million! Join the team and you may find yourself running alongside team patron Liz McColgan, triathlon captain, Alastair Campbell. There are events across the UK with distances for fun-runners and serious athletes alike! For more information visit [www.banana-army.com](http://www.banana-army.com).

If running isn't your thing, you can take part in one of our biking events across the UK for both children and adults. Visit [www.lrf.org.uk/cycling](http://www.lrf.org.uk/cycling)

## Driving palliative services

**Palliative care is benefiting more patients beyond the parameters of standard treatment. To access palliative care, patients require referral which can be difficult. This may be due to professional obstacles such as lack of knowledge or unwillingness to refer.**

Help the Hospices are launching a report, *Hospice and Palliative Care, Access for All*, which highlights the problems of gaining palliative services in the UK for many people. The report was launched to coincide with World Hospice and Palliative Care Day on 7 October 2006. Nurses who are interested in pushing the boundaries of care in haematology may want to use the report to initiate palliative services and will find it a useful tool.

For more information and to download the report, see the website: [www.worldday.org](http://www.worldday.org)

### More reading for initiatives in palliative care and haematology

- DoH (2003) *Building on the Best, Choice, Responsiveness and Equity*
  - DoH (2006) *NHS End Of Life Care Programme Progress Report*, Department of Health National Institute of Clinical Excellence (2003)
  - *Guidance on Cancer Services Improving Outcomes in Haematological Cancers — The Manual*. N.I.C.E.
  - National Institute of Clinical Excellence (2004) *Improving Supportive and Palliative Care for Adults with Cancer*. N.I.C.E.
- Useful web sites:**  
[www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk)  
[www.lcp-mariecurie.org](http://www.lcp-mariecurie.org)  
[www.cancerlancaire.org.uk/ppc](http://www.cancerlancaire.org.uk/ppc)  
[www.cancerimprovement.nhs.uk](http://www.cancerimprovement.nhs.uk)  
[www.nice.org.uk](http://www.nice.org.uk)  
 Courtesy of Kim Platt-Johnson, University of Leeds

## Haematology nurse appointments

**Kylee Shipp, Teenage Cancer CNS, at University College London Hospital (UCLH), took up post earlier this year. Kylee trained in Australia, and became involved in developing the teenage unit, funded by the Teenage Cancer Trust, at UCLH using her skills and experience gained over six years in the UK in various settings including HIV, haematology and adolescent care.**

Kylee said: 'Nursing teenagers requires specific care which matches this group's needs. When a young person has a blood cancer they are coming to terms with the changes in their bodies and have a range of concerns from losing their hair to a newly inserted Hickman line.'

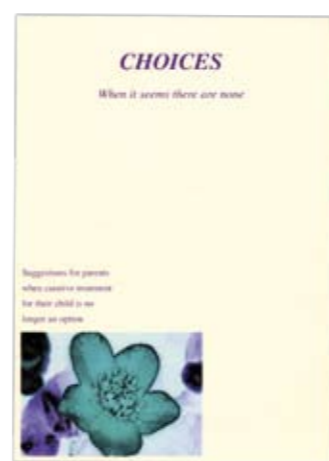
'The National Service Framework and NICE guidelines on teenage management is allowing nurses to establish formal structures for adolescents and young people with cancer care and haematology,' she added.



Kylee

Leukaemia Research Press

## Having choices



Treatments for childhood leukaemia have come a long way, with a success rate of 80 per cent. For those children whose prognosis is poor, however, families face a distressing time. The Leukaemia Research booklet *Choices* is available to health professionals who manage families facing unsuccessful recovery. Informative to nurses and their client base the booklet can be used in patient management to help parents come to terms with this difficult time and require understanding, empathy and follow up care beyond the treatment period.

To obtain a copy contact [medicalinfo@lrf.org.uk](mailto:medicalinfo@lrf.org.uk) or call 020 7405 0101 and speak to the Leukaemia Research information team.

## Upcoming events

### BSH 2007- Nursing Symposium

The British Society of Haematology 47th Annual Scientific Meeting will this year be held at the BIC, in Bournemouth, 30 April-2 May. The event includes a nurses symposium supported by Leukaemia Research. Visit [Leukaemia Research](http://Leukaemia Research) at stand 38 and find out about our patient information and the *Nursing Leukaemia campaign*.

For more information and to register, contact: Sara Lapsley, BSH Conference Organiser on 020 7387 5813 or email: [sarah.lapsley@b-s-h.org.uk](mailto:sarah.lapsley@b-s-h.org.uk)

### Annual conference — Investing in the Future

14 April 2007, Nottingham Crowne Plaza

Managing patients with blood cancers in today's health service is challenging. It requires an understanding of increasing developments in newer treatments which are changing the face of nursing care for the future. The Leukaemia Research conference looks at innovative research into haematological malignancies aimed at improving treatment and recovery from these serious diseases.

Come along and see the research of tomorrow making strides in treatments today. Nurses can pick up specific information at the *Nursing Leukaemia* stand with patient information booklets and resources for haematology nurses. For more details phone Rachel Porter on 020 7269 9008 or email: [rporter@lrf.org.uk](mailto:rporter@lrf.org.uk)

## New Information Booklets

Leukaemia Research continues to produce informative patient information with increasing contributions from specialist nurses. Our information team have added three new titles to our range of more than 40 free patients information publications.

- *Supportive Care (included in this pack)*
- *Acute Promyelocytic Leukaemia (APL)*
- *Donor Lymphocyte Infusion*

To order, please email: [nursing@lrf.org.uk](mailto:nursing@lrf.org.uk) or phone the information line on 020 7405 0101zz. Copies are also available to download on [www.lrf.org.uk](http://www.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. 24,500 people are diagnosed with a blood cancer in the UK every year.

**To find out more information, offer feedback or to suggest articles for future newsletters contact Livvy Fernandes, Nursing Leukaemia Co-ordinator at:**

020 7209 5030

[nursing@lrf.org.uk](mailto:nursing@lrf.org.uk)

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

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# NURSING LEUKAEMIA

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## Pacing care and treatment — palliative nursing in haematology



Livvy Fernandes, Nursing Leukaemia Co-ordinator, Ken Campbell, Clinical Information Officer and Katherine Nightingale, Clinical Information Associate at Leukaemia Research

**Leukaemia Research have produced an informative flyer about palliative care. Copies of *Palliative Care — A Summary Sheet for Nurses in Haematology* are available by emailing: [nursing@lrf.org.uk](mailto:nursing@lrf.org.uk) or by phoning Livvy Fernandes on 020 7209 5030 at Leukaemia Research.**

**Specialist haematology nurses are increasingly recognising the benefits of palliative services. Haematology patients may face a range of treatment dilemmas including unsuccessful drug therapy, where the stage of the disease is quiescent or the cancer may be untreatable — situations requiring alternative management.**

The medical profession have tended to focus on terminal care — historically,

the essence of palliative care. Many recent services assigned to palliative care are now being accessed by patients affected by chronic disease processes.

End of life care relates to death that occurs through age degeneration in one or more chronic conditions. It encompasses the individual's transition during this period requiring physical, psychological, or spiritual needs. In some haematological incidences end of life care may offer improved quality of

life, whether in healthcare environments like acute care, long-term care, hospice or home.

Symptom management, alleviating patient and family distress, giving appropriate information and resolving grief are key to nursing and those providing services. Patients with haematological malignancies are less likely to access palliative care services (McGrath, 1999; Hunt, 1997). However, there may be specific services which many patients with a haematological malignancy may benefit from but traditionally health services do not implement referrals.

Transfusions of blood platelets or palliative chemotherapy are specific examples where haematology patients may require supportive care. Livvy Fernandes, Nursing Leukaemia Co-ordinator, said: 'Both NICE and recent supportive initiatives enable nurses who work with diverse teams to ensure that their patients will receive appropriate palliative services. One of their strongest goals is to achieve patient pathways which allow them to make referrals in the haematology healthcare system.'

Getting healthcare staff and the general public to accept palliative care does not necessarily mean terminal care but leads to an understanding of optimal quality of life. The aspiration being that even patients who have no curable options to their disease will still be able to live a satisfactory life during disease degeneration.

**References**  
 McGrath (1999) Palliative care for patients with haematological malignancies — If not, why not? *Journal of Palliative Care*, 15, 3, 24-30.  
 Hunt, R (1997) Place of death of cancer patients: Choice versus constraints. *Progress in Palliative Care*, 5, 238-241.

## Australian nurses bridge the care gap

**A recent visit to Leukaemia Research forged new links with a sister blood cancer charity and its nurses in Australia. The Leukaemia Research Foundation in Queensland provides a range of support services to patients with leukaemia and their carers, families and friends.**

Barbara Hartigan, the Director Support Services at the foundation in Australia, said: 'It is comforting to know that even across the many miles support services,

information and research issues are similar and organisations such as ours are working towards finding a cure while caring for our patients, families and supporting health professionals everywhere.'

The charity's support is offered by telephone, face to face at home, hospital or at one of the foundation's purpose built accommodation centres depending on geographical and individual needs.

Like Leukaemia Research in the UK, the foundation funds leading research into better treatments and cures. Through its national research programme they have established the PWC Foundation Leukaemia and Lymphoma Tissue Bank and the Leukaemia Research laboratory at the Queensland Institute of Medical Research in Australia.

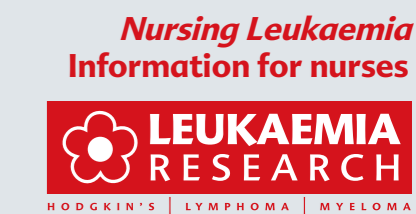
The Leukaemia Research Foundation,  
[www.leukaemia.com](http://www.leukaemia.com)



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Registered charity 216032

# Reaching a palliative platform in haematology

Palliative care interventions within haematology are essential if blood cancer patients are to benefit. Kim Platt-Johnson discusses the development and effectiveness of recent initiatives



**Nursing patients with haematological cancer demands integrated acute skills with confidence and competence in supportive care for those whose illness no longer responds to curative treatment. Many haematology patients will require palliative support, often from the point of diagnosis, with an emphasis on active intervention to maximise quality of life.**

Evidence is growing about the palliative care needs of patients. Feedback from patients identifies a need for services aimed at maximising independence and control as well as support for physical, psychological, emotional and spiritual needs. The haematological cancer nursing module at Leeds University is one example of how best local collaborative practice is aimed at addressing patient needs.

Despite evidence of initiatives aimed at appropriate use of palliative care, NICE (2003) identifies that there is weak but consistent evidence that palliative care interventions are used less in haematological cancers than in patients with solid tumours.

This may be due to lack of support or the inherent difficulties in identifying when certain interventions are inappropriate.

'The decision to change to a palliative approach may be taken too late or not at all, and persistence with aggressive treatment can cause great distress.' NICE (2003).

## National developments

Much emphasis nationally and locally is now being placed on breaking down the cultural and practical barriers that prevent appropriate collaborative work. The goal is to develop systems to enable us to work together to provide patient focused palliative care, regardless of disease, keeping patients in their preferred place of care, usually home, for as long as possible.

The NICE (2004) recommendation 'Improving Supportive and Palliative Care for Adults with Cancer' promotes a rehabilitative approach to care with emphasis on accurate assessment, goal setting and timely active intervention.

Over recent years there has also been investment in education for those involved in cancer and non-cancer palliative care services. The publication, *Building on the Best, Choice, Responsiveness and Equity* (2003) identified the need for training to enable those offering end of life care to feel competent and confident to do so. Twelve million pounds was identified by the DOH to support the implementation of best practice in palliative care.

## End of life care

The *National End of Life* initiative has been developed to promote appropriate access palliative care services equitably, regardless of disease. A national team is now in place led by the national director, Claire Henry. The initiative is responsible for the development of networks able to share local innovations, outcomes of evaluations and all palliative care education.

A range of clinical tools has been identified to enable best palliative care practice. All tools can be used with haematology patients with palliative care needs in primary or secondary care. These also include a preferred place of care document identifying the patient's wishes about where to die.

## The Gold Standard Framework

A tool initially developed to assist primary care teams supporting those in the last 6-9 months of life. The framework facilitates effective identification, co-ordination, communication of care. The sharing and recording of the wishes of the patient and their family are central to this process. It promotes anticipation of need and forward planning with an emphasis on the highest levels of team work and communication. It is aimed at avoiding unnecessary and inappropriate admission or intervention.

## Liverpool Care Pathway

This pathway has been developed to take the best of hospice care into hospital and other settings (DOH 2006). The emphasis of the LCP is to offer prompts to enable all teams supporting patients in the last days of life. Emphasis is upon anticipatory care, early identification of need and confident and competent management. The care addresses, spiritual, psychological, emotional and physical needs and places particular emphasis on care and support after death.

An initial evaluation survey of all tools concludes: 'Overall, the data demonstrates an increase in the roll out of the end of life care tools over the last year. However, the data highlighted a wide variation in the usage of the tools.' (DOH 2006)

National networks are being developed to support greater confidence and alliance to benefit patients and their families with palliative care needs. Despite this improvement, there is need for more services to explore the use of such tools in their practice. Haematology nurses are well placed to be catalysts for the integration of best practice from both specialties due to their unique role. Evaluations of the usefulness of such collaboration will further increase the growing body of knowledge available about the palliative care needs of this diverse group of patients in the haematology setting.

For further reading, see page 5

# Palliative care in clinical practice



Julie serving palliative services in haematology

## Palliative care — the clinical setting

The Ruth Myles unit:

- A 13-bedded ward with five designated BMT beds
- Internationally renowned for the treatment of non-malignant bone marrow failure, as well as haemato-oncology
- A tertiary centre for clinical haematology
- A centre for haemophilia
- The day care unit provides follow-up care for all the patients after chemotherapy and/or stem cell transplantation as well as providing a comprehensive apheresis service including stem cell harvests, plasma and red-cell exchanges

## Developments in the clinical area

- o Refurbishment of day unit
- o Expansion of nursing staff to four clinical nurse specialists

Julie Nicholson, BSc (Hons) Health Studies, ENB 237, ENB 998 is also Matron for Haematology at St George's Hospital, Tooting, London.

Julie Nicholson is a practice educator for haematology at St George's Hospital in London. Based at the Ruth Myles Unit, St George's has a dedicated palliative care team that consists of a consultant, senior registrar and three clinical nurse specialists. A close relationship exists between the haematology and palliative care teams which enable early and appropriate referrals.

The provision and nature of palliative care, depends on a number of factors like age of the patient at diagnosis, complexity of symptoms, poor prognostic factors and any co-existing morbidities that may influence the course of treatment as well as patient choice.

Julie said: 'The palliative care team will be involved at a very early stage, particularly if a patient is elderly and will probably receive non-curative chemotherapy. This is to ensure that they are referred to a community palliative care team attached to their local hospice.'

The patient then receives a phone call from the hospice, or a visit from the community palliative care nurse, to discuss hospice care and relevant support contact numbers. From the referral onwards, the palliative care team are involved in the patient care and are a great resource for patients and relatives for symptom control and ongoing psychosocial support. There is also practical help that can be accessed from the social worker that works between the hospice and hospital palliative care teams.

Julie said: 'It ensures that patients have a choice at the end of life between home, hospice, or hospital. These options will have been discussed at a time when the patient is in a position to make their wishes known, and the appropriate initiatives can be put in place in view of what they want.'

The unit use the palliative care team's expertise for symptom control, especially with patients who have intractable nausea and vomiting or pain during chemotherapy or bone marrow transplantation. Again they can make invaluable suggestions for pain control offering other options such as the TENS machine.

If patients relapse, have not responded to treatment or there are limited treatment options available, irrespective of age, etc the unit offers the specialist input of the palliative care team to aid with referrals, to get specialist help at home, appropriate

monetary benefits, and again act as liaison with the local hospice and community teams.

There is also an out-of-hours and weekend advice service provided by a registrar at the local hospice; this ensures that there are no delays in treating patient's symptoms.

During the last year, an integrated care pathway for the dying has been introduced into the trust; it is modified from the Liverpool care pathway. This has been successfully and appropriately utilised within the ward. Julie said: 'It gives the opportunity for nurses to discuss issues such as stopping blood tests, intravenous infusion and antibiotics with the medical staff. We encourage an open and honest dialogue. All viewpoints can be discussed and a plan can be formulated.'

'In some cases we have adopted the care pathway, but with provisos that we will continue to give platelet transfusions, to ensure that haemorrhaging does not occur. It has provided the flexibility that is required with this complex patient group,' said Julie. 'It also ensures that all the relevant people such as GPs are informed, that a full and open discussion takes place with the relatives, and the patient's spiritual needs are equally met,' she added.

It provides a tool so that the patient's comfort is paramount; Unnecessary interventions and excessive paperwork are reduced as it is a multidisciplinary team document that is provided.

The unit has had to offer shared care sometimes with the hospices, as they lack the facility to give platelet transfusions. Julie said: 'Although in an emergency they would give the platelets, the hospices do give blood transfusions as part of the symptom management. This means many patients still have to attend the day care unit, for prophylactic and routine platelet transfusions, although we are not actively treating their disease.'

The palliative care team has a very significant role to play in the care of patients with haematological malignancies, providing their own brand of expertise and knowledge that can enhance the patient's care and experience throughout treatment and at the end of life.

Reference: Ellershaw J, Wilkinson S (2003) *Care of the Dying — A Pathway to Clinical Excellence*, Oxford University Press, Oxford

# Working with uncertainty — how we can manage death and dying

*'You matter because you are you. You matter to the last moment of your life, and we will do all we can to help you not only to die peacefully, but also to live until you die.'*

Dame Cicely Saunders, founder of the modern hospice movement.

**Palliative care was formerly built on the ethos of management of pain, physical, emotional, social and spiritual distress which accompanied the dying process. How can this holistic approach be translated into haemato-oncology practice, where emphasis is on curative strategies in young patients who are at risk from their treatments as from their disease?**

We hope, in this brief article, to give some signposts from our own clinical experience in cancer and HIV care as to how acute and palliative care can work together.

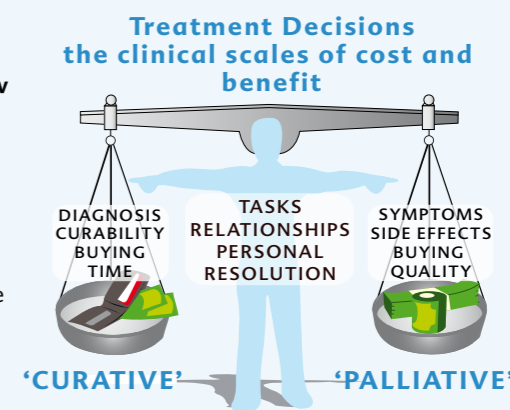
The relationship between cancer and palliative care is high on the political agenda, and the 'modernisation' agenda challenges staff to work differently and expand the health care team. For example, because of our ability to assist with symptom and communication, our skills with families and understanding of the emotional, social and even spiritual impact of sudden and extreme life-threatening illness, NICE states that palliative care should be available from diagnosis to death.

So what are the principal challenges and how can we deal with them?

## Patients and families

Liquid cancers affect the young as much as the old. Some will die soon after diagnosis; most will undergo highly invasive treatments that affect all areas of their life. Those who survive may well face a future of relapsing and remitting disease that may end in death.

Distressing symptoms are common and as much due to treatments as to the disease. At each point, the burdens and benefits of treatments will be different for the patient and family. You will see in the figure of cost and benefit, that the patient and not their disease is the fulcrum of decision making. The criteria for whether or not to be aggressive in treatment is determined by what patients want to do with their time, their relationships



and the life they have outside their illness. This needs physical strength and good symptom control, not just buying time at at any cost to stave off the decision day.

## Staff

The pace in haematology is very fast and the work intense. This carries a high cost for practitioners not just technically but with the emotional demands of long-term stays and repeated admissions. Naturally, healthcare professionals frequently develop strong relationships with patients, their carers and families. Investing a lot of themselves can be exhausting and if unsupported lead to burnout and poor staff retention.

A model of staff support, developed at UCL hospitals in the nineties, which worked well, was a weekly meeting on the haematology ward held by the palliative care consultant and CNS. Known as the 'Palliative Care Surgery', it ran at a time when anything to do with death and dying on a haematology ward was considered heresy. As the session was a staff clinic, however, we could allow the nurses (and junior doctors on occasion) to come and discuss particularly distressing and challenging cases whom the haematologists would not allow to be referred to 'specialist palliative care'.

This model of practice was felt to be empowering to both the ward based staff and the palliative care team. It provided an environment in which nurses could express difficult and sometimes overwhelming emotions. It was the critical bridge that allowed the two services to integrate.

## Challenges

Traditionally, palliative care has sat in hospices, with a clear remit for terminal care. The advent of NHS hospital palliative care teams in the early eighties, brought the hospice philosophy into mainstream NHS services. That said, it is not an easy road to travel for nurses who have elected to work with patients and families at the end of life.

There is still much work to be done in the clinical setting for staff at every level. Those of us in palliative care have had to learn to be flexible, responsive, fast working practitioners, who are able to work creatively with front line staff where the emphasis has been on curative strategies. In other words, helping all concerned to 'live with uncertainty'.

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