Welcome to the summer edition of Haematology and Bone Marrow Transplant News. It has been quite a busy time for the Steering Committee in planning for the national education events, preparing our fringe event for Congress and developing our action plan for the next year.

The Steering Committee now has Welsh representation, which is great, and as Chair, I am excited to have haematology nursing representation from all four UK countries on board.

This is your newsletter and we would welcome articles, stories, and examples of good practice for publication. Our aim is to be a conduit, disseminating knowledge as well as being a newsletter for discussion. If you have any suggestions, please get in touch.

We hope you enjoy reading this edition.

Let’s hear all about it!

MARVELLE BROWN, Forum Chair and Newsletter Editor, looks forward to reading your news.

New Steering Committee members

A big welcome, or croeso, to Miriam Atkinson and Noreen Lewis, our new Welsh representatives on the Steering Committee.

Miriam Atkinson, RGN, Diploma in Professional Practice, Postgraduate Certificate in Counselling, Stem Cell Donor Manager, Welsh Bone Marrow Donor Registry.

Miriam qualified in 1986 from Bristol and Weston School of Nursing. Following surgical and medical experience, she specialised in bone marrow transplantation and acute haematology, gaining 15 years’ experience in University Hospital Wales. Miriam gained her Diploma in Professional Practice in 2002. In the same year, she took up her post as Stem Cell Donor Manager in the Welsh Donor Registry. She is clinically responsible for a caseload of voluntary, unrelated stem cell donors, involving counselling, consenting, harvesting and clinical follow-up.

In 2003, Miriam gained a Postgraduate Certificate in Counselling. Later that year, her abstract, on communicating news of patients’ deaths to stem cell donors, was selected as best abstract in a donor setting and was presented at the international conference at the National Marrow Donor Programme, in Minneapolis, USA. This study was published by the Nursing Standard in 2005.

Noreen Lewis, Haematology Lead Nurse, University Hospital of Wales, Cardiff.

Hello everyone.

Recently co-opted onto this committee, I have been in nursing for 27 years and have been in haematology for the majority of that time in various areas of the specialty and at all grades. I progressed to my present position of Haematology Lead Nurse in October 2005, a role that was initially funded by Macmillan.

The University of Wales is the only level four centre in Wales and is a busy haematology and bone marrow transplant (BMT) centre. My role is exciting and rewarding and its purpose is to provide professional leadership and direction to nurses working throughout the directorate and to give specialised nursing advice to the South Wales Haematology Network. I am privileged to work alongside a dedicated, motivated and experienced nursing team that aims to give expert care to patients and support to their relatives.
An introduction to myeloma

Myeloma is the second most common bone marrow cancer, with over 3,700 new patients diagnosed in the UK each year. Although myeloma is not curable, there are an increasing number of treatment options available. MONICA MORRIS, from Myeloma UK, reports.

Epidemiology and aetiology
In myeloma, a single defective plasma cell (a myeloma cell) multiplies rapidly, disrupts the immune system and crowds out normal haemopoietic cells in the bone marrow. Myeloma cells have an affinity to bone, leading to bone damage and pain – the most common and distressing factor of the disease. The disease is characterised by periods of treatment and varying periods of remission. With current treatment, the median survival is approximately three to five years.

The average age of diagnosis is 70 years, with only 2 per cent of cases under 40 years. There is an increased risk in the Afro-Caribbean community and a reduced risk in the Asian community. The risk of myeloma is possibly linked to exposure to petrochemicals, certain heavy metals and radiation, but the exact causes are not yet known. The development of myeloma may be a result of a number of factors coming together.

Symptoms and staging
As well as pain, hypercalcaemia, pathological fractures and spinal cord compression are also symptoms of myeloma bone disease. Other symptoms of myeloma include recurrent infections, anaemia and fatigue. High levels of paraprotein in the blood and urine can cause renal dysfunction and raised plasma viscosity.

The staging of myeloma is dependant on measuring albumin and ß2-Microglobulin. Further prognostic information can be gleaned by chromosomal analysis, morphology, plasma cell turnover and serum LDH. Certain cytogenetic abnormalities are associated with poorer prognosis – these include deletions of chromosome 13 and certain translocations of chromosome 14 – t(4;14), t(14;16).

Treatment of myeloma
If treatment is indicated, standard treatment options include chemotherapy, steroids and thalidomide. Melphalan or cyclophosphamide are commonly used chemotherapy agents. Thalidomide was first used as a treatment for relapsed disease, but is now increasingly used as a primary treatment. High-dose therapy and autologous stem cell transplant is still regarded as the treatment of choice for patients under 60 years, and may be considered in people up to the age of 70.

Bortezomib (Velcade®) is a newer treatment used for relapsed or refractory myeloma and is currently being assessed by NICE for NHS use. LENalidomide (Revlimid®) is another new targeted treatment that offers a further treatment option, and it is likely to obtain marketing authorisation shortly. The recent expansion in new therapies means doctors are faced with the challenge of knowing the optimum way to use these treatments, as well as overcoming the difficulties around access to new cancer treatments in today’s NHS.

GET INVOLVED!
The Steering Committee is planning to draft together competences for haematology and bone marrow transplant nursing. We believe that having such competences endorsed by the RCN will give further credibility to our speciality and could be used as a basis for the Knowledge and Skills Framework (KSF). Ultimately, having some consistency of standards will further improve patient care. When the draft is written, we would welcome comments, feedback and suggestions. If you are interested in being involved, please get in touch with Marvelle Brown via email. We look forward to hearing from you.

Supportive care
Bisphosphonate treatments have been shown to reduce bone pain, skeletal events and improve quality of life. As such, they are recommended for all patients with myeloma requiring treatment with chemotherapy, whether or not bone lesions are evident. Effective pain control is a priority of care and there are a variety of pain-relieving methods, including local radiotherapy and opiate analgesia.

Symptomatic anaemia (caused by both the disease and chemotherapy treatment) is managed by the use of blood transfusion or recombinant human erythropoietin (EPO). Antibiotic therapy, IV immunoglobulins, haematopoietic growth factors and vaccinations, are all used to treat or prevent complications associated with immunosuppression.

Adequate hydration (three litres daily) is essential to both prevent and treat renal impairment. Renal failure occurs in 3–12 per cent of patients and is managed by dialysis.

Information and support
Myeloma UK provides information and support to all those affected by myeloma and aims to improve treatment and care through education, research, campaigning and awareness. For more details of all Myeloma UK’s programmes and services, visit www.myeloma.org.uk

Myeloma UK works closely with nurses through its innovative MAGIC for Nurses programme. A core part of MAGIC is nurse education about myeloma; MAGIC Education Days are held in various locations in the UK and Ireland each year, and the modular, self-assessment Myeloma Nurses’ Learning Programme is used by many nurses worldwide. If you want to find out more about MAGIC for Nurses, email: magic@myeloma.org.uk or telephone Monica Morris on: 01932 789 145.
Life on the fringe
A report from the successful Haematology and Bone Marrow Transplant Nursing Forum fringe event, held at RCN Congress, April 2007.

We don’t need specialist nurses, do we?
With so many interesting fringe events available at Congress, nurses were spoilt for choice. After a considerable amount of worry from the Steering Committee members as to whether nurses would attend our fringe event and concerns over whether one of the main speakers would show (they were stranded somewhere in the rail system), we had a very good very good debating session.

A great result
We had an excellent turn out, and the room was filled to capacity. The event was attended by nurses from a number of specialities, including critical care, diabetes, rheumatology, blood transfusion and haematology, demonstrating the interest and importance of this sensitive issue. With changes being made to the role of clinical nurse specialists (CNSs) nationally and at local level, we were on to a winner. This was reinforced by Patricia Hewitt, stating, a week before Congress, that clinical nurse specialists were not cost effective!

Forum Chair Marvelle Brown led the discussion, opening with a presentation that gave a strong and passionate case for clinical nurse specialists, but with a caveat, pointing out that they needed to do more to make their role recognised, validated and respected.

As part of her case for clinical nurse specialists, Marvelle highlighted the delivery of expert care, underpinned by high-level, in-depth clinical assessment skills, clinical decision-making and clinical judgement, which reflects the CNS role. She added that the clinical judgement and leadership of the role has significant positive impact on reducing length of hospital stay and reduced complication, both of which have been evidenced in a number of articles.

Worth the cost?
Marvelle went on to say that clinical nurse specialists are value for money and they, along with other health care professionals, are at the forefront of modernising the health service. As well, she said that clinical nurse specialists shape education, practice, research and management for the benefit of the patient.

A myriad of national documents advocate the need to invest in more specialist personnel to support patients and carers through their pathways. As a result, it is now the ‘norm’ for clinical nurse specialists in haematology to be core members of their multi-disciplinary team. It is often difficult to quantify the activity of a clinical nurse specialist, and many argue that their contribution to service delivery can be seen as a ‘luxury’; however, anecdotal evidence suggests that this is not the opinion of service users.

Further suggestions
RCN Rheumatology Nursing Forum Chair Sue Oliver stated it was a very difficult time, that nurses were suffering information overload and needed to look at the whole picture. She felt that maybe forum chairs needed to get together to look at the role and seek out specific advice and support. She stated that this should come from the regional RCN office, which could point in the right direction. RCN Adviser Sue Thomas, who has been doing some work around redesigning nursing, indicated that she would like to hear the views of nurses.

Speakers discussed how the principles of the role should be the same, whatever speciality nurses work in. It was clear from the discussion that patients depend on clinical nurse specialists, but when working in small group, it can be very isolating and lacking in support – it was also very evident that clinical supervision and peer support wasn’t readily available, yet was really necessary to function at this level.

It was suggested that the RCN needed to have a group to disseminate good practice on these issues, and that what was needed was a virtual community so people could talk to each other online, perhaps on a web page, to share concerns and practices.

In future …
As members of the Haematology and Bone Marrow Transplant Nursing Forum, we agreed to take this away and look at working with the RCN to take this forward. We would love to hear your views. Write in to the editor, via email: marvelle.brown@tvu.ac.uk , and we will publish your comments, views, and opinions.

No small change!
Bursaries available …
The Steering Committee is proud to be able to offer two bursaries for nurses wanting to attend and/or present at a relevant conference. Up to £400 per nurse will be offered for conference fees, accommodation and travel. Requests for the bursary should be made to the editor no less than six weeks before the conference. Successful applicants will also write an article about the conference for the newsletter.

What’s in a name?
The Steering Committee is considering changing the name of the newsletter and we would welcome your suggestions. We want a name that is snappy and fun, but that reflects our speciality. Send in your suggestions by 1 September to the editor via email. The winner will receive 30 pounds’ worth of book vouchers.
Reporting back on a worthwhile conference

Some notes from the European Haematology Association (EHA) Conference, held 7–10 June 2007, in Vienna.

I have been fortunate enough recently to obtain funding to attend EHA and was very impressed with both the quality of the talks and the organisation of the event. The location was an added bonus and the use of my annual leave to attend the conference was well worth it.

**Good communication is essential**

Graham Jackson bravely role-played delivering bad news in a scenario that portrayed an intensive therapy unit (ITU) referral for a bone marrow transplant patient. This was an emotive and highly interactive session, which, as always, showed good communication to be the key to best practice. The speakers were also explicit in the fact that nurse specialists and ward nurses were an integral part of this process.

The myeloma talks at EHA echoed those at the British Society for Haematology (BSH) and concurred that vincristine, adriamycin and dexamethasone (VAD) chemotherapy would be replaced by C-Thal-Dex as the gold standard for the disease. Indeed, preliminary data indicates that this regime appears to be as effective as autografting for myeloma.

**Three in a row ...**

This is an excellent conference that had something for everyone, with all the diseases within haematology covered. It is a shame, however, that all the haematology conferences are so close together (European Blood and Marrow Transplantation, BSH and EHA within three months of each other). The nursing element of BSH is growing and will need to receive our support, but – as work commitments continue to grow – attending all conferences becomes difficult. If you do get the opportunity for any of these conferences, however, they are well worth it. EHA is not only for medical staff – it was very beneficial from a nursing perspective and extremely worthwhile.

**Noreen Lewis**

Steering Committee member

---

**Haematology Directorate Cardiff and Vale NHS Trust**

Sharing the dilemmas and getting it right! A one-day conference, to be held Monday, 26 November 2007, at Miskin Manor, 9am–4.30pm, which will look at all the issues shared by the oncology, palliative, haematology and general specialities.

Topics will include:
- breaking bad news
- intensive therapy unit (ITU) admissions
- a patient’s perspective
- transition from acute to palliative care
- end of life pathway
- recruiting into trials
- implications of caring for a Jehovah Witness
- needs of the non-malignant patient such as sickle cell and haemophilia.

Conference fee is £35 and includes refreshments, lunch and certificate of attendance. To secure a place, please contact Susan Hancock on email: Susan.hancock@cardiffandvale.wales.nhs.uk or telephone: 02920742111. Cheques to be made payable to Cardiff and Vale NHS Trust.

---

**LOOKING AHEAD**

The Steering Committee will hold its next meeting and education event in Northern Ireland, 18 September 2007. The programme for the education event will be:
- using photospheres for graft versus host disease (GvHD)
- special blood requirements
- HLA tissue typing
- an overview of sickle cell disease and thalassaemia.

The event will start at 12.30, with lunch, finishing at 5pm.
- venue TBA
- cost is £10 for all.

Places are limited, so early booking is recommended. Contact the editor for further details.

**COURSES**

**Thames Valley University**
- Certificate in personal and professional development in advanced management of adults, children with sickle cell disease, thalassaemia and related conditions (designed for multi-professionals) – March, 2008 start.
- Bsc (Hons) professional practice with clinical haematology – October 2007, January 2008 start.

For further information on these courses, please contact Marvelle Brown at email: marvelle.brown@tvu.ac.uk

**University of Central England**
- For courses related to haematology and oncology, with various start dates, contact Tracey Burgoyne at email: tracey.burgoyne@uce.ac.uk

**DON’T FORGET ...**

... to get in touch with stories you like us to publish!