

Nursing a teenage trouble – young people with blood cancers

Teenagers and young adults have specific needs which are distinct from those of children or adults. Indeed, this period of life is filled with change, adjustment and emotional unrest unlike other times.

Nurses managing young patients with leukaemia and blood cancers require not only therapeutic and nursing skills to match, but an understanding and empathy which relates to the young person's cultural and social world.

Teenagers and young adults may often find themselves nursed either on children's wards or adult units, who by their very nature do not have the unique skills and experience to cater for this generational group.

Teenage cancer units have gone some way in achieving optimum clinical management and an access to research trials for patients, although the expansion of these units nationwide is slow.

Many leading experts in adolescent care have already recognised that although childhood survival rates have increased significantly over the last 30 years, adolescent and young adults have not had similar responses.

Louise Soanes, Senior Sister for Children's Services, at the Royal Marsden Hospital in Surrey, said: 'Nurses are bringing attention to teenager needs. Health care practitioners, patients and charities have done much lobbying to raise the profile of teenagers and young people with cancer, but more is still to be done. Access to clinical trials is still an area that needs to be addressed. Nationally, teenagers and young people with cancer, even children, are not included in the Government Cancer agenda.'

What happens at the ward level may well be on par with what occurs in clinical research. The UKCCSG (www.ukccsg.org) maintains the register for childhood cancer. Not enough young



Communications & Press: Royal Marsden NHS Trust press office

Louise Soane, Senior Sister, believes that teenagers should be addressed

people over 16 years are entered into clinical trials. Experts say that approximate 40-60 per cent of patients aged 15-19 years enter national leukaemia trials, compared with 75-90 per cent of children under 15. This shortfall still lies alongside the paucity of teenage services.

A new booklet by Leukaemia Research *Young adults with a blood cancer — What do I need to know* explores important issues surrounding this age group who are affected by a haematological malignancy. See www.lrf.org.uk/youngpeople or contact medicalinfo@lrf.org.uk



**Virtual tour of
adolescent
management**
Page 2



**A nursing
approach to
young people in
research**
Page 3

**Nursing Leukaemia
Information for nurses**



Virtual reality – nursing teenagers in non specialist areas

Teenager cancer units bring with them a sense of excellence, so what happens when young people are not nursed in specialist centres? Many health professionals, now advocating that young people benefit from expert care, are attempting to address the needs of teenagers admitted to young children's or older adult wards.

Gill Harley, Macmillan Clinical Nurse Specialist for Teenagers and Young Adults with Cancer, at the NHS Lothian University Hospitals Division, runs a 'Virtual Unit' which brings teenage services to young people throughout south-east Scotland. The service was set up four years ago and an estimated 30 new patients are referred annually.

Alongside a social worker, she provides support for newly diagnosed patients and for those affected by relapse or recurrence. Gill said: "Patient referrals come from a multidisciplinary team, through consultants or clinical nurse specialists. Those from adult haematology, so far, have been our greatest success."

The team follow a philosophy of care which spans across diagnosis to treatment and follow-up. According to the patient's diagnosis and age, Gill assesses patients for specific management including the specialist pain team, paediatric psychiatrist, adult psychologist and primary care teams.

As a Clinical Nurse Specialist, Gill sees herself as a voice for patients, their families and staff in a variety of situations. She said: "The service goes to where the patient is, whether in adult, paediatric or district general hospital. It's putting across to consultants a young person's decision about treatment, especially if it differs from the consultant's. We help staff understand the parent role and what it is like for a young person being treated with older people or children." Gill also

regularly reviews facilities for young people including helping them to access their entitlement to benefits.

Disrupted education

In developing services Gill liaises with educational institutions and primary healthcare teams. "If the young person agrees I contact their school, college or university and meet teachers. I may assist planning their studies, organise a break or set up a distance-learning programme. I discuss with home tutors and plan education to fit around their treatment."

She will also offer to meet peer groups or pupil tutor groups to support the young person's friends and answer questions. If the young person is unable to sit exams whilst undergoing intensive treatment, Gill will contact invigilating boards. She has even invigilated exams in homes and hospital.

Her contact with primary healthcare teams (PHCT) involves explaining her role and supporting GPs and district nurses who rarely see patients with leukaemia. "I offer to do a joint home visit and can attend PHCT meetings to explain treatment plans. Should contact between the family and the PHCT have broken down – if there has been a long delay in a teenager getting diagnosed, for example, I can act as a mediator."

Listening and support

Her nursing practice is pivotal in support and counselling her adolescent patient group. "The skill is being available," Gill said. "Listening to what they are saying and not what other people think they are saying. Hanging on in there, even when they are pushing you away. I provide my client group with age-appropriate materials, like DVD and CDs, to occupy them in hospital and will offer to attend appointments with them."

She draws heavily on education around diagnosis and treatment and giving support during times of critical decision making. "I make sure patients, parents and siblings have correct relevant information



Gillian reaching teenagers in Scotland

so teenagers are able to make informed decisions for themselves. I help them to pass this information to other professionals. We also organise two support groups."

Not all teenagers will survive a blood cancer and Gill provides palliative care plus any family bereavement follow-up. "This is a difficult area for staff alongside a lack of expertise. Patients in adult hospices have an average age of 70 years and there are few paediatric hospices. In our region, one is situated centrally and families may have to travel for several hours to get there. Young people may have to accept their parents caring for them after being quite independent – they are not children; but can end up being treated like children."

Common Issues for Young People with Cancers

A diagnosis with cancer disrupts the growth and development of a young person.

The NHS Lothian 'Virtual Unit' address the common issues of young people

- Loss of independence
- Change of body image
- A disrupted education due to illness
- Difficulties establishing a career
- Adjusting to sexual development versus potential sterility
- Loss of friends and loneliness
- Lack of privacy
- Fatigue and mood swings
- Life after treatment

Nurses recruiting young people in research



Carly Leighton trained as degree nurse in Australia later working in medicine and renal dialysis, but a move to the UK in 2001 led her to make a career change to haematology.

“On arriving in the UK, I worked on the nurse agency in a variety of settings,” Carly said. “Eventually, I had the opportunity to work on a haematology and bone marrow transplant unit (BMT). I found it challenging with patients undergoing intensive therapies, but felt extremely well supported by my nursing colleagues.”

It was on a 18-bedded nurse-led unit at the University College London Hospital (UCLH) that Carly gained specialist nursing skills and knowledge. Four beds were sponsored by the Teenage Cancer Trust for adolescents undergoing treatment for leukaemia, lymphoma or BMT. Over three and half years Carly drew a deeper understanding of the disease and the impact that treatment regimes had on patient’s lives.

Last year, she was offered the post of Oncology Research Nurse for Paediatric Adolescent Oncology Services at the Middlesex Hospital in West London. Consolidating her experience with teenagers and her interest in cancer treatments, she said. “I had developed a ‘soft spot’ for the teenagers on the unit and when the opportunity for a research nurse became available within the Trust, I jumped at the chance. As a ward-based nurse you have an ‘individual focus’ to

your work. Being a research nurse gives me a broader perspective on what is happening with all young cancer patients within the NHS trust who are treated on protocols.”

Paediatric oncology research has improved considerably since the introduction of the UKCCSG in 1977. The development of this group has brought with it an overall improvement in the way in which paediatric cancer is treated and managed and has resulted in extending our knowledge of the disease.

The research portfolio at UCLH has expanded from five to 15 paediatric clinical trials. Patients range from three to 18 years of age. They include UKCCSG trials such as PNET studies for a variety of brain tumours, Wilms tumour, high risk neuroblastoma and Hodgkin’s lymphoma (recently closed but their second most active trial in terms of patient recruitment). They also run MRC trials – AML 15 and UKALL2003 for the acute lymphoblastic leukaemias (ALL). The latter is their biggest recruiting trial with more than half of patients being teenagers.

One of Carly’s main roles is to explain UKALL 2003 trials to her young patients and their relatives. As they have three years of treatment, this can have a major affect on their daily lives. Carly feels teenagers in this group need specific management to meet their concerns, and said: “It impacts on their school or college, friends and themselves. Sometimes it means a return to dependence on their families when previously they have been moving through a transition to independence. There is also the potential for infertility. My nursing history in haematology has made this information giving much easier, as I have a good working knowledge of ALL and its treatment.”

Carly coordinate’s with registrars, SHO’s and senior nurses to ensure that the minimal residual disease (MRD) samples arrive safely at the designated lab. She establishes strong links with the multidisciplinary team (MDT), particularly nurses from inpatients and day care, who play a pivotal role in communicating with the patients and the MDT.

UCLH strive to improve the research process for patients and alongside clinical trials they are monitoring the well being of patients. This includes additional studies as a Quality of Life Questionnaire. This needs to be given to patients at diagnosis and then at various time points during their treatment.

Carly said: “It has been a steep learning curve for me in terms of learning the regulations and guidelines governing this research in the UK. It can be an extremely difficult time for newly diagnosed patients. To be able to help them work through this and see them develop an understanding of their disease and it’s treatment can be extremely rewarding.”

The role of the paediatric oncology research nurse

- Explain and inform about individual trials to young audience and family
- Explain treatment investigations
- Explain to leukaemia patients about MRD and its role in the treatment of leukaemias in the young
- Explain about specific research methods eg randomisation
- Provide specific information regarding the haematological disease, chemotherapy during induction and ongoing treatment
- Co-ordinate blood sampling/tissue sampling for genetic and biological studies
- Ensure nursing and medical staff involved in sample collection are fully instructed about handling and transfer
- Forging links with MDT who see each patient from diagnosis to follow up

- UKALL2003 at UCLH is led by Consultant Paediatric Oncologist, Stephen Daw at UCLH
- AML 15 (adult protocol with paediatric appendix) at UCLH is led by Professor Tony Goldstone, chief investigator for the trial in the UK

The adolescent whose parent has been diagnosed with cancer

Being diagnosed with a blood cancer is overwhelming for family members as much as the individuals involved.

When parents are told that they have cancer, preparing their children for what lies ahead can be complex and daunting.

Alison Finch, Sister at the Haematology and Bone Marrow Unit at University College London Hospital, has worked with young people affected by parental cancer.

“At a time of personal change, coping with a parent’s diagnosis can leave the adolescent feeling a sense of isolation with little support,” Alison said. “Young people can feel they have to be careful about what they say in case they upset their parent. At the same time they think they should remain emotionally strong.”

Alison feels that adolescents can demonstrate strength and resourcefulness in adapting to their parent’s illness. Having completed a small-scale project at UCLH she feels that nurses should be aware that support goes beyond diagnosis, and said: “Many young people said that they coped well and had grown closer as a family through their experiences. Support should be viewed in the long term in helping adolescents cope over

time. As adolescents may be fearful of the hospital environment and hesitant in talking to professional staff, my work advocates initially working with patients to help support younger family members at home.”

Nursing practice should approach parental cancer as a family concern.

Alison recommends:

- Heightened awareness amongst staff about the impact of parental cancer on family members.
- Promotion of a family focus to admission assessments, so staff can gain an understanding of younger members perception of parent’s illness and provide appropriate support.

Communication and support at diagnosis may be crucial to a family’s long term coping over time, throughout curative treatment or in the event of relapsed disease.

- Alison Finch RGN, BSc (Hons), MSc. To find out more about Alison’s work with young people, email her at alison.finch@uclh.nhs.uk



Alison supports young people whose parent maybe diagnosed with a blood cancer

Useful journal references for the nurse management of adolescents:

- Albritton, K and Bleyer, WA (2003). The management of cancer in the older adolescent. *European Journal of Cancer*. 39 (18). pp2588-2693
- Smith, S (2004). Adolescent Units _ an evidence based approach to quality nursing in adolescent care. *European Journal of Cancer*. 8 pp20-29
- Whiteson, M (2003) The Teenage Cancer Trust _ advocating a model for teenage cancer services. *European Journal of Cancer*. 39 (18) pp2688-2593
- National Service Framework for Children, young people and maternity services (DoH 2004)

Open days

Leukaemia Research Open Days bring together the best of scientific research into leukaemia. Nurses can update their knowledge about diagnostic methods, future treatments and potential cures for these serious diseases.

Bristol – 8th October

UBHT Education Centre (opp. Childrens' Hospital) Central Bristol

Liverpool – 22nd October

Department of Haematology, 3rd Floor Duncan Building, Royal Liverpool University Hospital

Call Rachel Porter at the Leukaemia Research for more details on 020 7405 0101

Teenage cancer services: More than just a tantrum

Young people's experiences of healthcare

- Only 12 per cent of 16-17 year olds are treated on adolescent wards
- 58 per cent of teenagers are nursed on childrens' wards, even though they would like to be nursed on adolescent wards
- One third are nursed on adult wards
- 64 per cent of young patients received information about their care and treatment which was easily understood by them
- 63 per cent are able to discuss their worries and fears with nurses
- 76 per cent are confident and trust the nurses who treat them
- 60 per cent 'definitely' and 30 per cent to 'some extent' feel nurses give them support and comfort
- Only 51 per cent feel nurses who treat them know enough about the young person's condition or treatment; an additional 34 per cent feel most of the nurses know enough

Source: *Patient Survey report 2004 – young patients* by the Healthcare Commission

Nursing a running smile



Work or at play, Jeff is used to running around

Caring for patients with a haematological malignancy is rewarding, if sometimes challenging. One person who has surpassed his endeavour in haematology is Jeff Horn, Haematology Clinical Nurse Specialist (CNS), from Aberdeen Royal Infirmary. This year he ran the London Marathon and raised over £2,000 for Leukaemia Research.

Jeff has been in haematology for 10 years, working as a staff nurse and chemotherapy nurse. He became a CNS two years ago, and said: "The complex and very specialised nature of many haematological conditions and the intensive nature of modern therapies

means that this group of patients greatly benefit from the support of a CNS – both through direct care and through the 'behind the scenes' work that isn't always recognised."

Jeff previously ran for the International Myeloma Foundation at the BUPA Great North Run. He said. "This year I decided to push my limits and aim for marathon distance. I ran the Flora London Marathon for Leukaemia Research mainly due to the wide range of haematology diseases that the charity supports. Running for the charity means that the money I raise will benefit the greatest number of people with

a variety of conditions, not just those with leukaemia."

Despite various hitches during his training, Jeff completed the marathon in 4 hours and 28 minutes. "I enjoyed just about every one of the 26.2 miles. What makes London so special is the incredible support from other runners and the massive crowds of spectators. The noise from the crowds as you pass Buckingham Palace and turn into the Mall is deafening. What really made the day for me, was the encouragement from the other members of Leukaemia Research 'Banana Army' and their supporters – complete with giant inflatable bananas!"

Adolescent health in haematological malignancies

Common physical effects of young people undergoing chemotherapy

- Nausea & vomiting
- Weight loss/gain
- Fatigue
- Alopecia
- Anxiety
- Sore mouth
- Loss of fertility
- Anaemia
- Thrombocytopenia
- Neutropaenia
- Changes in taste and appetite

Psychological considerations for teenagers with blood cancers

- Altered body image
- Sadness, depression
- Separation from peers
- Anger
- Relationship changes
- Sexual dysfunction

Source: references provided by Louise Soanes, Royal Marsden Hospital. (See journal references)

Want to take part?

Want to join the BANANA ARMY in 2005? Call 020 7269 9001 or e-mail: running@lrf.org.uk or visit our website www.justgiving.com/bananaarmy



Haematology Nurse Appointments



Press & PR Dept: Blackpool Victoria Hospital

Anne Donovan

Macmillan Clinical Nurse Specialist, Anne Donovan, at Blackpool Victoria Hospital took up the post earlier this year. She has worked in haematology for 18 years gaining a wide experience on inpatient wards and day care. Her interest has culminated in a recent haematology nursing course at Thames Valley University.

She said: "One of my first jobs has been to ensure that patients have access to support and information that they need. I am delighted as part of the multidisciplinary team to help develop a patient-centred service for Blackpool and the surrounding area."

About Leukaemia Research

Leukaemia Research Fund 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 Fund 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.

Cell mates

28-29 October 2005
Hanover Hinckley Hotel,
Leicester



Final call for registrations!

The two-day conference is a joint collaboration with the RCN Blood Transfusion Nursing, RCN Haematology and Bone Marrow Transplant Forums in association with Leukaemia Research and *Nursing Leukaemia*, to raise awareness for these three specialist areas.

Celebrity Guest Speaker: Angela Baker, whose real life experience inspired the film 'Calendar Girls'.

The main programme includes patient experiences from blood transfusion to blood cancers, accountability, advanced practice, cancer networks, NICE Guidelines and research into leukaemia. Concurrents will take place in blood, HBMT and leukaemia.

For further information please contact:
Sonia Lynch, Conference and Events Organiser,
Royal College of Nursing, on 020 7647 3849 or email:
bloodHBMT@rcn.org.uk



Tell us about it!

Nursing Leukaemia has over 600 nurses receiving information from Leukaemia Research. We are always looking for interesting nurse-led stories in haematology for our news magazine and web pages. Whether you work in the clinical setting or bringing patients to essential clinical trials for blood cancers, we would like to hear about the important work that you do.

Please contact Livvy Fernandes, Nursing Leukaemia Co-ordinator, at lf Fernandes@lrf.org.uk

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



020 7209 5030



nursing@lrf.org.uk



www.nursing-leukaemia.org.uk



Leukaemia Research Fund
43 Great Ormond Street
London WC1N 3JJ

Registered charity 216032