Leukaemia CARE
Autumn 2005

focus

Caring for people affected by the leukaemias • Hodgkin's and other lymphomas • myeloma• myelodysplasia • myeloproliferative disorders • aplastic anaemia

Committed to the CARE Line

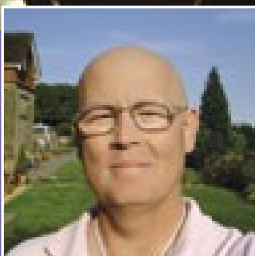
Have **you** heard about the **CARE Line?**

As our flagship service – the 24 hour CARE Line – goes from strength to strength, we are calling on everyone to spread the word (and number!) to ensure that all newly diagnosed patients are aware of this service.

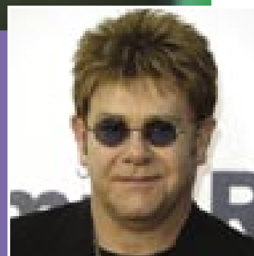
It is our vision that every patient and their family and friends become aware of how we can support them, should they feel they need it, and that there is always someone at the end of the phone for them, day or night.

We know that every year around 24,000* people are diagnosed with leukaemia, lymphoma or an allied blood disorder. Not all of these patients will want or need our care and support, but we believe that nearly 5,000 patients, carers and their families could really

WHAT'S INSIDE



Coping with hair loss
Looking at ways to improve any hair loss



Your chance to see Elton John for free!
See back cover for details on how to enter this fantastic competition

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"Leukaemia CARE is a charity committed to providing care and support to everybody whose lives have been affected by blood cancers - simply supporting a quality of life for all"

Spreading the word

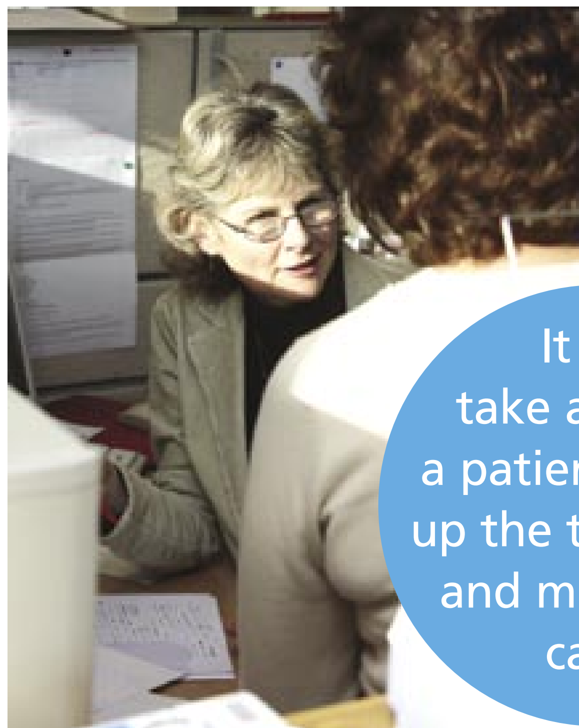
benefit from calling the CARE Line, and using our support services.

The key to reaching these people is to substantially increase national awareness of the CARE Line freephone number and the support that is available from our CARE & Support Team. But our aim to provide care and support to everybody whose lives have been affected by blood cancers will only succeed if we have support from everyone concerned to help publicise the CARE Line number where possible.

The CARE Line remains a unique and much envied service amongst cancer charities throughout Europe – a tribute to all those involved that a Charity of our size has been able to maintain and improve the CARE Line service, free to callers, 24 hours a day, 365 days a year.

In line with our strategic plan, we are firmly committed to expanding and developing further this vital service. Through the support we have received from your donations and fundraising, with significant financial support from several major pharmaceutical companies, we are now able to take another step towards our goals for the CARE Line. We are delighted to announce new opening hours at the CARE Line offices, where we will be open from 8.30am to 10.30pm by employed staff. We are in the process of recruiting and training additional personnel to increase our CARE Line team, which will ensure we have the resources to extend these essential care and support services.

The CARE Line continues to be open 24 hours a day, with our dedicated team of trained CARE Line Volunteers ensuring that calls outside our office opening hours are answered, and that a listening ear is there for you whenever you need it. We are currently strengthening our CARE Line Volunteer team with three new operatives. These Volunteers have been successfully supporting patients



It can help to discuss the best way to support a patient's particular problem

> It can take a lot for a patient to pick up the telephone and make that call...

and carers already, yet as CARE Line operatives they must also successfully undertake training to qualify to offer telephone support to patients and their carers, via the Telephone Helplines Association (THA). We are extremely grateful to our CARE Line Volunteers for their continued dedication and commitment to helping us provide this vital 24 hour service.

So if you have benefitted from calling the CARE Line, or you know someone who has, please help us to 'spread the word'.

You can ring the CARE Line, which is staffed by a dedicated team, whenever you need help and support. We are available 24 hours a day, 7 days a week. Just call the freephone CARE Line number... we'll be there when you need us.

You could be a patient, carer or family friend who might, amongst other things, need:

- A listening ear or befriending - sometimes you just need to talk to someone who you are sure will understand;
- Information on alternative treatments, like homeopathy or aromatherapy, or relaxation therapies like reiki or massage;
- Financial assistance - paying bills, transport for hospital visits;
- Help and information on diet, fatigue, hair loss, etc. - we have booklets which provide more information;
- To talk about bereavement and/or choosing to die at home;
- Information on travel insurance and other financial services - we can put you in touch with organisations where grants can be applied for;
- Advice on welfare or benefits; or
- To know how to support a patient or carer who might not be related, such as a pupil, neighbour or work colleague.

Always there... always care!

Call us on the CARE Line
0800 1696680

Charity Message

It is with great pleasure that I wish all our readers a Happy and Healthy New Year for 2006.

This year promises to be a very exciting one for Leukaemia CARE, building on the success of 2005, when we moved into our new premises. We made so much progress last year and I am confident that we will enjoy many new developments and improvements over the coming months.

We have received significant corporate donations recently, which have enabled us to complete the internal construction and decoration of the CARE Line area, and to start on the development of the CARE treatment rooms and rest area. I would like to praise the team for all their efforts in securing these funds, and long may it continue.

We hope to have an official opening of our new premises during this year, with a major celebrity performing the ceremony for us, which we will announce nearer the time!

I was delighted to welcome so many of our Volunteers to our first Volunteer Conference in the new building. Thank you for giving up your time to attend, and for all your messages of support and encouragement – please read the report on the conference on pages 16-17.

I hope you find some articles of interest to you, and please do let me have your feedback on any of our publications and their content.

Our Volunteers and staff are still tirelessly giving their time and efforts to ensure we continue to provide care and support to patients and their families, and I thank them wholeheartedly for this.

Finally, our thoughts are with you, and please remember, that we are always here for you, day and night.

Clive Hatt,
Chairman

Transplantation procedures and principles

Stem cell transplantation (SCT), using stem cells in blood or in the bone marrow, is widely used in the United Kingdom and throughout the world as a treatment for children and adults with blood disorders and other genetic problems. The main reason to do a stem cell transplant is to cure somebody with leukaemia. It is one of the most complicated and expensive procedures performed by the National Health Service. This article will explain the reasons for doing the procedure, the principles of the procedure and some of the side effects patients can expect.

What is a stem cell transplant?

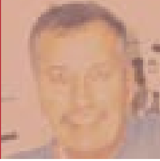
A stem cell transplant is a 'rescue' technique used to treat your illness in which your existing bone marrow is destroyed and replaced by new bone marrow and/or blood cells.

Reasons for stem cell transplantation

These include acute myeloid leukaemia (AML), acute lymphoblastic leukaemia (ALL), chronic myeloid leukaemia (CML) and increasingly chronic lymphocytic leukaemia (CLL) where there is a less than optimal response to non-transplant treatment. More recently some of the major indications for transplantation include myelodysplastic syndromes (MDS) and lymphoma. CML now has a very good non-transplant treatment with Imatinib and transplant is mainly reserved for people who do not respond to this treatment or very young people who have an excellent chance of being cured by transplant. The use of transplant in AML and ALL is uncontroversial when the leukaemia has relapsed but it is also used in first remission. Whether this is better than the non-transplant therapy of these leukaemias depends on the individual and the precise characteristics of the leukaemia they have. Myelodysplastic syndromes have no other curative therapy and transplant is being increasingly used. Many patients with MDS are older but new transplant strategies get around this problem. SCT can now produce prolonged disease-free survival in patients with relapsed non-Hodgkin's lymphoma, Hodgkin's disease and chronic lymphocytic leukaemia. Many of these patients have very good survival with non-transplant therapy and transplant is usually reserved for people who have relapsed.

Principles of the procedure

Patients are admitted to hospital and given high doses of chemotherapy and sometimes radiotherapy that aim at killing all the malignant cells in the bone marrow and in other organs. The infusion of fresh clean stem cells from a normal donor (a graft) that matches the patient then rescues the patient from this marrow failure and these cells home their way to the bone marrow space where they produce normal red cells, white cells and platelets. However there is an additional and very important effect. Some of the lymphocytes in the stem cell infusion recognise the malignant cells in the patient's body as foreign and attack them. In the case of a patient with leukaemia this is called a graft versus leukaemia effect and is believed to be very important in eradicating the disease. The high dose chemotherapy and radiotherapy is usually well tolerated and patients need not fear that they will be nauseated or vomit because there are excellent drugs available to prevent this. However patients do need to have a certain level of fitness to tolerate the procedure. More recently mini-transplants with low doses of chemotherapy or radiotherapy have been developed which make more people eligible for the procedure. These transplants rely on a graft versus leukaemia effect.



Visiting a transplant patient means having to wear a plastic apron, and using the alcohol rub on your hands before and after your visit to reduce the risk of infection.

Expected side effects

Some very predictable side effects occur in the first two weeks before the bone marrow cells make fresh blood cells. Patients lose their hair but this will grow back four to six months later. As there will be no marrow function for a while patients need red cell transfusions, platelets transfusions and have a high chance of developing an infection due to a low white cell count. Most of these infections can be treated very well with intravenous antibiotics and it is not common for people to become seriously ill during the initial phase of a low white cell count. The worst initial side effect is a very sore mouth (mucositis) which sometimes requires very strong pain killers and many patients are unable to eat and require intravenous feeding (total parenteral nutrition).

The major side effect of transplant is graft versus host disease. This is where white blood cells in the transplant (graft) recognise normal tissues in the patient as being foreign and attacks them. This can affect many organs in the body but principally affects the skin, the gut and the liver. Early on this is called acute graft versus host disease but after three months it is called chronic graft versus host disease. Graft versus host disease can be treated with drugs such as steroids but also can be serious. SCT can affect the function of vital organs including the heart or the liver because of the high doses of chemoradiotherapy. A thorough assessment of organ function prior to transplant is necessary. Transplants can be rejected but there are strategies to deal with this serious complication.

Long term effects

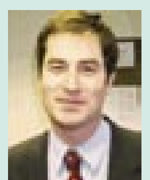
Chemotherapy and radiotherapy can affect transplant patients' fertility. This requires detailed discussion before transplant as sometimes fertility can be retained. Sometimes transplant causes the thyroid gland to function poorly but this can be treated with thyroid hormones. Radiotherapy and steroids can cause cataracts but there is a good operation for this. Another serious potential long term effect is an increased chance of a cancer. Some of these cancers can be successfully treated but it is important to try and prevent them with screening for cervical cancer and breast cancer and careful skin care. Reporting symptoms early on is also important.

The goals of treatment

The aim of all allogeneic transplants is to cure the patient and provide them with a good standard of life. If that is not possible then the aim is to substantially prolong the patient's life, again to a good standard. Some leukaemia patients who have transplants early in the course of the disease have very high chances of cure, but they also have an upfront risk of not surviving the transplant. The decision whether or not to have a transplant requires considerable thought and discussion with friends and family. Sometimes transplant is the only curative option and then the decision is more straightforward. There are good booklets available about transplant and the author advises that potential transplant patients know as much about the procedure as possible before entering into it. Fortunately the United Kingdom has large numbers of excellent transplant units where patients can receive care as good as anywhere in the world.

Transplant patients are often in hospital for up to six weeks and may be unable to work for six months or longer, this has a profound affect on a patient's family and finances. This is a very worrying time but social workers are available to help patients and their families going through these procedures.

However, if you are still worried or concerned, please call the **CARE Line** on **0800 1696680** for more information.



Dr David Marks is currently the Lead Clinician on the BMT Unit at Bristol Royal Hospital for Children.He is also the Director of Adult Allogeneic Transplantation, President Elect of the British Society of BMT, Chairman of the Clinical Trials Committee of the British Society of BMT, NCRN acute lymphoblastic leukaemia working group and a member of six working parties for the Centre for International BMT research.

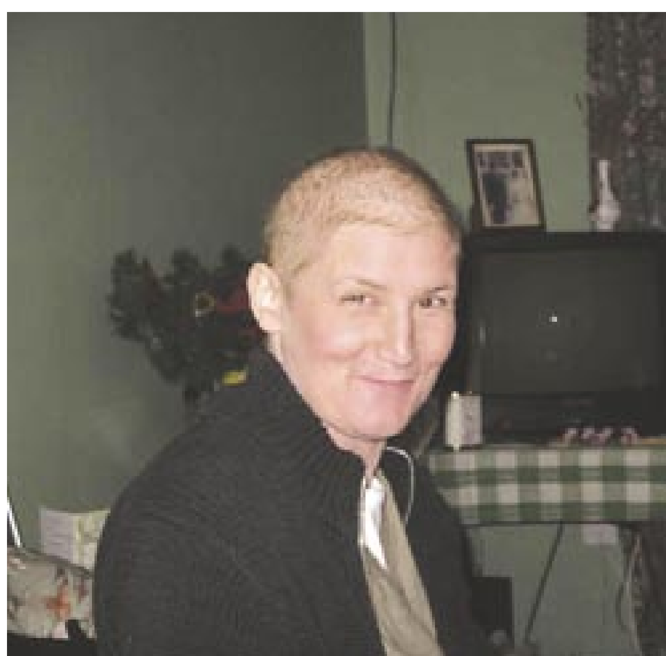
Coping with Hair Loss

Hair loss – or Alopecia – is a common side effect of chemotherapy. However, it can affect people in very different ways. If you are having difficulty adjusting to your hair loss, Dr Hilary Thomas explores possible ways you can cope with your new look.

Hair loss or alopecia is a relatively common side effect of several chemotherapy agents. It is also a side effect of radiotherapy to the scalp.

With chemotherapy the risk of developing alopecia depends on the type of drug used, its dose and the schedule used (eg. every three weeks or every week). In addition there is also wide variation from patient to patient as to whether they will experience hair loss after a particular drug. With a drug that causes alopecia in the vast majority, some patients won't develop it at all, whereas other patients can develop alopecia when it is not a usual side effect of the drug.

It is important to read the small print on the information leaflet for any chemotherapy agent. Where hair thinning is described, the extent of this hair thinning can vary widely between individuals. It is certainly worth asking someone from your medical team how severe the risk is of a wig being necessary.



Women, in particular, can experience fluctuating emotions when they are seen by others outside their immediate family and friends.

Scalp cooling

Some years ago, when I had a sizeable breast cancer practice, we looked at cooling the scalp with cold caps of patients receiving Epirubicin and Adriamycin as adjuvant therapy for breast cancer. We distributed a questionnaire to about 50 patients, and generally had very positive feedback. The majority of patients liked feeling that they were in control and being able to do something for themselves, even if the scalp cooling wasn't successful. Some found it difficult to tolerate, but the vast majority found the first few minutes uncomfortable, but after a while became used to the sensation and were able to tolerate it.

The principles of scalp cooling are to cool the blood vessels which supply the scalp, and thereby reduce the blood flow to the scalp. In this way the chemotherapy does not reach the hair follicles and on this principle the hair is not so likely to fall out.

Alternatives

Of course, there are alternatives to scalp cooling and these become relevant where it doesn't work. The majority of patients will wear a wig when they lose their hair. I usually encourage my patients to make a treat out of it. One of my patients recently discovered the shop which supplies wigs to Joan Collins and Joanna Lumley. Certainly the trip up to London may you cheer you up more than waiting for the regulation NHS wig. That said, the NHS wigs are very good, and I think we are now well past the days when people were given wigs that looked very obvious and ill-fitting.

It may help to go for a wig fitting while you still have some hair. In that way you will be able to choose a wig which is similar to your own style. I have also suggested to patients who are having their scalp cooled to have their hair cut beforehand. If hair on the head is thinner, it is easier for the cold cap to fit more snugly and cool the scalp more effectively.

Alternatives to wigs include hats, hair-bands and bandannas. These can look

very elegant and are preferred by some patients. Going bald is also an option and one more likely to be pursued by male patients or younger women. The important thing is to know yourself. I have certainly had patients who, like Mo Mowlam, could not tolerate a wig in hot weather and so simply took it off as she notoriously did in a cabinet meeting.

Talk about it

The important thing is to know how important hair loss will be to you. For many patients it is a difficult psychological barrier and looking in the mirror at their bald head

The majority of patients find that their hair grows back much thicker than before

is a constant reminder of their cancer. If avoiding alopecia is important to you then discuss it with your doctor. It may be possible to use different drugs, or use the same drugs in a different way to minimise the risk of hair loss.

Some drugs, such as Paclitaxel, may result in the loss of eyebrows and eyelashes. You should have been warned about this, as this also makes a significant difference to your appearance. For many patients they will look more different without their lashes and eyebrows than without their hair.

If you call our **CARE Line** on **0800 1696680** they have information booklets which can suggest ways to cope with hair loss.

There are drugs that are said to cause hair loss, but this can be ameliorated. When the Taxane drugs (Paclitaxel and Docetaxel) were first used they were widely reported to cause alopecia. However giving Paclitaxel on a weekly basis at a lower dose or giving Docetaxel with the cold cap can prevent this side effect for many patients. Furthermore I have anecdotal experience of giving Topotecan using the cold cap. Although I have only treated a handful of patients in this way, four out of five of those who could tolerate the cold cap have been able to keep their hair.

There is one silver lining to this story, and that is that the majority of patients find that their hair grows back much thicker than before. A well known footballer's wife lost her hair with her treatment for ovarian cancer. When it grew back it was very thick and she described herself as a sonic hedgehog! In addition it often grows back more curly than before, and for the majority of patients this is an added bonus.

'Cold caps'

Hair loss may be prevented by wearing a Cold Cap sometimes called 'scalp cooling'. Cold caps act to cool the scalp and therefore restrict the blood circulating in that area. This reduces the amount of chemotherapy drugs reaching the hair follicles, so the hair is less likely to fall out.

The cap is put on fifteen minutes before chemotherapy to start restricting blood flow, and kept on during and up to 1-2 hours after your chemotherapy. The cold cap will make you feel cold all over, so wear a jumper or ask for a blanket and a hot drink. You may find that the cold cap gives you a headache.

Cold caps may not be a suitable treatment for everyone. Some people cannot tolerate wearing the cold cap as it can feel very cold. This discomfort varies from patient to patient so it is not a failure if you can't wear it and it has no influence on the outcome of your treatment.

It works for most chemotherapy durgs, although you may still lose some or all of your hair despite using it. Also, it may not be a suitable treatment for your condition, so you should always discuss your options with your medical team.

Dr Hilary Thomas is currently Medical Director at The Royal Surrey County Hospital and Lead Clinician, Surrey, West Sussex and Hampshire Network. She took up the post of Professor of Oncology at the University of Surrey in September 1998. In October 2001 she took up the post of Macmillan Network Lead Clinician to the Surrey, West Sussex and Hampshire Network. She currently has four sessions of clinical work, four for the Network and three for research and teaching at the University. Her main areas of clinical interest are in gynaecological cancer.

How can your **District Nurse** help?

When you are discharged from hospital after a long stay, it can be a huge shock, mentally and physically, to be back at home.

From having 24 hour nursing care, you can experience many feelings of concern now that you have to fend for yourself. This is when the district nurse service can really help.

What is the District Nursing Service?

The District Nursing Service consists of teams of staff nurses and nursing auxiliaries led by a District Nursing Sister/ Charge Nurse. They work alongside other health care professionals such as doctors, Macmillan nurses, health visitors, practice nurses and community psychiatric nurses. They also work closely with Social Work and Home Care Services, provided by your local council.

What does a District Nurse do?

District Nurses play a crucial role in the primary health care team. They visit people in their own homes or in residential care homes, providing care for patients and supporting family members. As well as providing direct patient care, district nurses also have a teaching role, working with patients to enable them to care for themselves or with family members teaching them how to give care to their relatives. District Nurses play a vital role in keeping hospital admissions and readmissions to a minimum and ensuring that patients can return to their own homes as soon as possible.

How can they help me?

The aim of the District Nursing Service is to help you and your family or carer cope with the effects of your illness, particularly when your illness stops you from being independent and being able to look after yourself. The service provides nursing care to children and adults of all ages and their carers in their own homes.

This may include care:

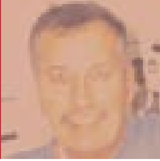
- for people who have a long term illness
- for people who have come out of hospital after an operation or treatments
- at home to prevent people having to go into hospital
- for people who are terminally ill, and require palliative care.

On your first visit, the District Nurse will discuss with you and your carer the level of care you will need, and a Care Plan will be drawn up and left with you. Some district nurses have been trained specifically to provide support to haematology patients, including giving chemotherapy at home. You will need to enquire if there is a haematology district nurse in your area.

District Nurses also provide much needed emotional support, at a time when you may want to talk about your hopes and fears as your condition progresses.

How do I get to see a District Nurse?

The GP or hospital staff may suggest that the District Nurse would be of assistance to you, and they should inform your GP and the District Nurse that you have been discharged. However, you or a relative or friend can contact the District Nurses directly; your local health clinic can provide their contact numbers.



To **support** you on your **Journey**...

Following the success of our CARE booklet, which we launched three years ago, we have introduced another booklet into our CARE series, called 'Journey'.

Once you have been on your cancer journey for a while, many patients are quite knowledgeable about their condition, and feel that the information available is mainly directed towards newly diagnosed patients.

However, we recognise that you may still need support and information and, as your condition is an ever-changing picture, questions will still arise that you want answers to. In fact, it can be *more* difficult to ask questions when you are an existing patient, as you are conscious of not wanting to distract the nursing staff with your problems. Your questions are still extremely valid though, and are very important to your medical team.

To help you look forwards, Journey includes a section on further questions which have been suggested by patients and carers. The Haematology section features more detailed explanations, and there is a new section on current treatments. We understand that you probably have different priorities now, and so we have also introduced new sections on Nausea, Fertility and Life after Leukaemia. To encourage you to keep up a diary, there is also a section for tracking your bloods.

The Journey booklet will shortly be available on ward, but please request a free copy from the **CARE Line** on **0800 1696680**.

Hospital chaplain comes up trumps

When Joan Wallace, a Leukaemia CARE Volunteer from the Isle of Lewis off the North coast of Scotland, became ill with cancer, she expressed a wish to see her son again.

Joan, who is terminally ill, had not seen her son, Russell, for 14 years as he lives in America and through residency issues cannot leave. The hospital chaplain, Pastor Calum Russell at the Western Isles Hospital in Stornaway, came up with the idea to set up a webcam link from Joan's hospital bed. After speaking with the hospital's IT engineer, they managed to set up a laptop on the ward, and Russell set up the link at his home in New York.

Joan was overjoyed to see her son after so long. She said *"Although I could not touch him, I could see him and it meant a lot.*

"I want to say thank you to the chaplain and the technicians who helped set it up. I cannot thank them enough. I hope that this can be done to benefit other patients."

Joan feels strongly that more should be done to prevent paperwork from keeping families apart.

We would like to know if you have been in a situation like Joan's.

Leukaemia CARE Volunteer wins Award

Roger Van Cauter, long serving Volunteer in the West Midlands region, has received an award for commitment to Leukaemia CARE and Macmillan Cancer Relief as part of the Community Services Volunteers (CSV) Year of the Volunteer initiative.

The Lord Lt of Shropshire presented Roger with his medal at a ceremony at Shrewsbury Abbey on 13 December 2005. Roger (pictured right with his wife, Diane) said: *"I lost one of my daughters at a very young age to leukaemia and my other daughter has also undergone treatment for cancer. As a result I am well aware of the good work that these charities can*

provide to people affected by cancer and have been inspired to get involved with volunteering, fundraising and campaigning," he said.

Eve Martin, National Care and Support Manager, praised Roger's efforts: *"Roger is one of the Volunteers who are working hard to promote the care and support offered by Leukaemia CARE. He and all our Volunteers are a vital part of our team and we applaud their efforts and thank them whole-heartedly."*

Let's talk about...

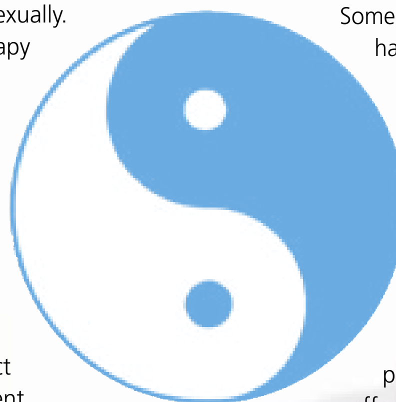
Problems with sex

Overcoming the embarrassment of talking about a sexual problem is the first step to getting the help you need. Dr Maxine Stead suggests how to approach the situation.

Not everybody who is diagnosed with cancer will be sexually active or in a sexual relationship, but for those who are, the diagnosis and the treatment given can sometimes affect how they feel about sex.

This may be because of the shock of the diagnosis itself and the readjustments they have to make to their life. Sometimes it is because of the treatment they are given. For example, they may feel very tired during chemotherapy and might not have any energy for sex.

Sometimes specific treatments can affect how people feel sexually. For example, chemotherapy may result in hair loss, which may make a person feel differently about themselves and this might affect their feelings towards sex. Unfortunately doctors and nurses do not always talk to people about the possible impact of cancer and its treatment on their sex life.



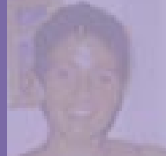
Why does talking about it help?

If someone is not told that a treatment might affect how they feel about sex or that there may be difficulties with intercourse, it can be a shock if they then experience sexual problems without knowing why. (Difficulties here can range from dryness of the vagina to the inability to achieve or maintain an erection.) They may feel unusual or odd if no one has told them that there might be difficulties and they could think that they are the only person having such problems. It is often reassuring to know that there is a reason for such difficulties and that there are other people also having similar problems.

If you have a problem that began after you were diagnosed with cancer, then your doctors and nurses should be able to help you. Sometimes, sexual problems happen several months after treatment and people do not realise that their current problem may be associated with the treatment. It is important to ask for help about any new problems that have started since your diagnosis. Some hospitals and GP surgeries have special clinics or staff who can help with issues like sex.

Why do doctors not mention the subject?

We are trying to encourage doctors and nurses to speak to patients about the possible affects of treatment on sexual functioning and research is ongoing to look at just how treatments affect different groups of people. Ideally, doctors and nurses would inform people about the possible impact of their cancer treatment on their sexual activity beforehand, but this does not always happen. By encouraging people to raise the issue themselves, healthcare professionals will increasingly realise that sexual matters are important, and this should encourage them to talk to more people about the likely effects.



How can I talk to my doctor about sex?

If your doctor or nurse does not talk to you about sexual issues, how can you get help? It is sometimes embarrassing to talk to other people about such a personal issue. When your doctor asks, 'Is everything else okay, or you having any other problems?', it is not very easy to say, 'Well actually doctor, I'm having problems with sex'!

But do remember that your quality of life is a very important aspect of your care, and doctors and nurses are dedicated to helping you enjoy your life as much as possible – in addition to helping to treat your disease. Your doctor may refer you to Relate who are the UK's largest provider of sex therapy, but you can go to them direct. Find out more at www.relate.org.uk.

Will they be shocked?

Do not be concerned that mentioning sexual issues or asking about a sexual problem will shock your doctor or nurse – they might be embarrassed but they should listen to you. We live in much more open times nowadays and sex is not so much of a taboo subject as it used to be. People (including doctors!) are less shocked to hear about older people being sexually active, for example, or about people having a relationship with a partner of the same sex.

Does my doctor have time to talk about it?

It can sometimes be difficult to ask the doctor or nurse about any problem because you feel under pressure to keep the appointment short. But it is still worth mentioning any difficulties – otherwise the problems might go on and on! In many cases the doctor or nurse can give advice or help straight away (such as suggesting the use of lubricants or different positions for intercourse). Or they might arrange to see you on another day so that they can spend more time talking to you about the problem and trying to help you overcome it.

How can I raise the subject if I have someone there?

It can be difficult to talk about sexual matters if you are with your partner, or a friend or family member, when you see the doctor. You could ask the person you are with to wait outside while you see the doctor or ask to see a nurse in private. Or you could ask the nurse for their telephone number and arrange to speak to them about the problem later.

Can I read up about it?

Our **CARE Line** can provide you with helpful booklets from CancerBACUP about how cancer can affect sexual activity and your feelings about sex. You may find it explains everything you need, or that it could help you talk to your doctor about sexual problems. Alternatively, you could read it through before your next appointment so that you are aware of the types of problem that might occur as a result of your treatment. This could make you feel more confident about asking a question.

Dr Maxine Steed graduated in 1993 with a degree in Pharmacology and Physiology from Leeds University. She worked at the Clinical Trials and Research Unit (CTRU) in Leeds for eight years as a Trial Manager. Whilst at the CTRU Maxine completed a part-time psychosocial PhD entitled 'Identification and assessment of quality of life issues in patients with cancer'. Maxine currently works at the UK Clinical Research Network Coordinating Centre as Assistant Director coordinating clinical research across the country.

Although it can take courage to talk about sexual issues, it is worth it if it means getting the help you need to keep that part of your relationship healthy and fun! If you would like to talk over any problem, please remember the **CARE Line** team are always there to listen to you talk on **0800 1669 6680**.

My name's Alan, I'm 61 years old, married to Heather and have two children Matthew and Paul. We live in Warwickshire and have been very well looked after by Dr Galvin at Walsall Manor Hospital. I've had an artificial leg since 1962, which may not seem relevant to my CML (Chronic Myeloid Leukaemia) at first, but actually had quite an effect on our life after my stem cell transplant.

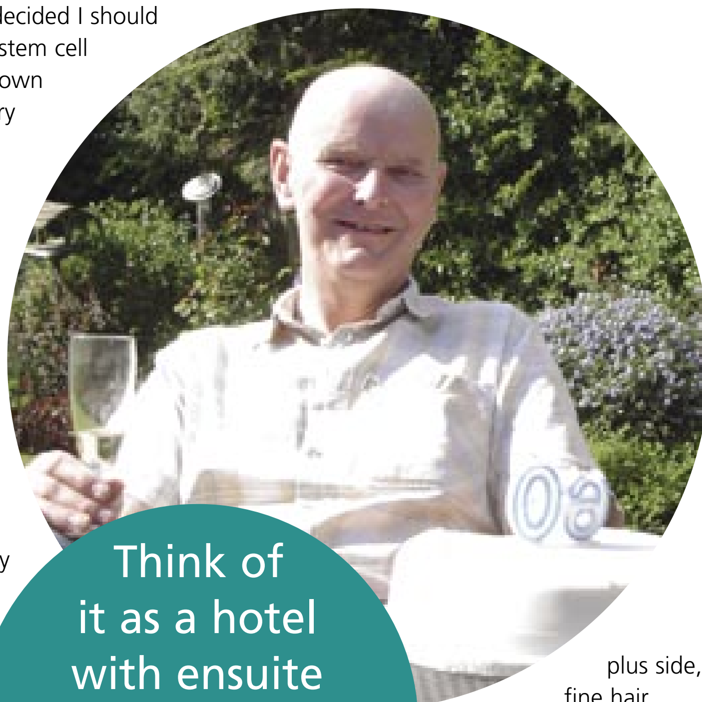
During the summer of 2001 I lacked energy; I felt very tired and had night sweats. I thought I was suffering from the male menopause, having read various articles in the press. When I started to lose weight, I went to see my GP who thought it might be leukaemia and sent some blood off for testing. After two days I saw a consultant and blood tests confirmed I had CML with 100% Philadelphia gene.

This was a terrible shock to me and my family. From the booklet we were given it indicated I only had 5-6 years to live!! We didn't fall apart though, and our friends and relatives were very supportive. Life was also quite busy, backwards and forwards to hospital, every visit seemed to take at least 3 hours. Apart from the time I was in hospital, I have continued to work as an engineering consultant.

My stem cells were harvested for possible use in the future. In October the treatment was changed to Interferon Alpha injections to try and reduce the Philadelphia gene count. I injected myself, which was no problem, but the interferon made my joints painful, so I took paracetamol several times a day. The pain was worse after being still for a while, particularly after driving the car. A bone marrow transplant was considered, but my sister was not a match and there was no unrelated donor. This was a great disappointment as this was the only possible cure.

After six months there was still no reduction in the Philadelphia gene count so I was changed to the new wonder drug, Glivec, which was being trialled at the time. We thought this was going to make a big difference. It controlled my blood counts, but had no effect on the Philadelphia gene, so I was referred to Professor Goldman at Hammersmith Hospital, London.

Professor Goldman decided I should have an autologous stem cell transplant using my own stem cells. In February 2004, while I was at work, I had a phone call saying I had a bed, so off Heather and I went to Hammersmith. Heather stayed with me in my room for the whole of the four weeks. Without her being there, time would have really dragged. She was my true support!



Think of it as a hotel with ensuite facilities, 24 hour room service and free drugs!

The chemotherapy and other drugs started – 34 tablets every six hours. Our son, Matthew, developed a web site where we left a daily report and friends could leave messages. I had to go on a "Clean Diet"- no eggs, salads, nuts or dried fruit. Then my hair started to fall out so they shaved it all off and I had to stop wearing my artificial leg to prevent the risk of infection from blisters etc. This meant I had to use crutches for the first time for 40 years, it was hard work, painful and frustrating.

The actual transplant was painless, just like a blood transfusion. As my blood counts fell I became very susceptible to infections, so my visitors had to wash their hands and wear plastic aprons. As one of the consultants said "think of it as a hotel with en suite facilities, 24 hour room service and free drugs!". My mouth became very sore but the dietician supplied me with fortified drinks and soups. Heather was a great help, making the soups and encouraging me to drink them. My blood counts increased slowly, except for the platelets, I had to have platelet transfusions 3 times a week. I still couldn't wear my artificial leg until my platelet count reached 50 though, which was a complete pain.

Food tasted different for quite a long time and my appetite was poor, but on the plus side, fine hair started to grow.

After four weeks we went home, this was a worrying time, after having excellent medical support on tap 24 hours a day, we were now on our own.

In October the platelet count reached 24, having at one stage dropped to one and, disappointingly, it was decided to stop the platelet transfusions. I had my first haircut in October and my count slowly increased, at Christmas they reached 40, without any transfusions. I started to walk with crutches which made an amazing difference to our lives.

It's now December 2005 and I feel very well, leading a normal life and still taking no medication for the CML. My platelet count is now 217, a great increase from one; when my white cell count reaches 30 they will harvest my stem cells again, and after that they will try me on Glivec again to see if it reduces the Philadelphia gene. Hopefully there will soon be a drug available to me that will eliminate the Philadelphia gene altogether.

We greatly appreciate the help the help and support the NHS has given us over the last four years.

Alan Humphries

If you see someone without a **smile** today...

Give them one of yours!

It was with great sadness that we said farewell to our dear friend Pat Durrant, who passed away on 7th November 2005.

Pat had been a member of Leukaemia CARE since 1996, and having committed to giving time as a Volunteer, she became the Regional Co-ordinator for Wales region in 2003. Still a patient with chronic myeloid leukaemia, she managed her illness very effectively, becoming an inspiration to family and friends.

Pat left a letter to be read at her funeral, and we wanted to include an extract from her words, which is pure Pat. Even if you weren't lucky enough to meet her, her positive attitude to life and her illness inspired everyone who spoke with her, not to mention the smile she had for everyone.

Pat, pictured centre, with the CARE Line team.

"To all of you present, please do not be sad today. I have had a great life.

Thank you Brian, my partner of the last 18 years, for introducing me to the world of sailing. Through you I learnt to swim and snorkel and experience the magic of the sea and the coral reefs. We sailed down all the West Indian islands, and then to St Kitts and Nevis, St Maarten and the British Virgin Islands. On to Bermuda and the States where we docked in Newport, Rhode Island. Another summer saw us in Nova Scotia and along the eastern seaboard of the USA. Eventually to the Abaco islands in the Bahamas where we spent several months. We had some great times, we met lots of interesting people. I learnt a lot about myself and other people during these long voyages, from my favourite position on the sailbag on the stern soaking up the Caribbean sunshine.

I have been blessed with very many good and loyal friends too numerous to mention by name. We have had some wonderful times together and I shall still be with you when you are walking in the mountains, canoeing in the Mawddach or sailing.

I want to say a big thank you to my healers and all the people both in hospital and elsewhere who have helped and supported me through the last nine and a half years since my diagnosis. You have all been a wonderful comfort and support to me, kept me full of energy and allowed me to enjoy life to the maximum whenever I could.

Thank you to all my massage patients. I hope I made your lives a little easier along the way. Now I'm off to massage the angels – I'm sure their arms get very tired!

I'd also like to say thank you to all the wonderful people I've met through Leukaemia CARE in the last few years. I hope I've been useful to some of you: I know you've helped me.

Now, I have a special request. I would like you to walk up Moelfre just once a year, to sit there a while and meditate. Moelfre is my favourite mountain and one which I often visited in times of personal dilemmas.

Now I am off to explore another dimension. I have packed my rucksack so there had better be some good walks.

Do not be sad. Enjoy each day as if it might be your last. Time is so precious – do not waste it.

Finally, I add my own special philosophy: if you see someone without a smile today: give them one of yours!

Pat