

15<sup>th</sup> March 2010

## Patients reveal the truth about life with Leukaemia On the web

The mix of shock, confusion, disruption and relief faced by people with leukaemia is brought to life today as 46 people tell their stories on the web via 250 video, audio and written clips.

The experiences have been coordinated by researchers at Oxford University for the award-winning website [www.healthtalkonline.org](http://www.healthtalkonline.org).

This latest section offers a characteristically honest and comprehensive insight into the experience of being diagnosed and treated for the disease for leukaemia sufferers, their families, and the healthcare professionals who look after them.

The research, conducted by the Health Experiences Research Group at the University of Oxford was funded by The Kay Kendall Leukaemia Fund and Leukaemia Care.

It found that prior to diagnosis, most sufferers had thought leukaemia was a single illness that only affected children. In fact, as the range of interviews reflect, Leukaemia is the collective name for a spectrum of blood cancers with dramatically different prognoses.

People in the largest group - with *chronic lymphocytic leukaemia* (CLL), a slow-growing but incurable form of the disease, had been particularly shocked. Many found it reassuring that the condition was slow growing, but others found it difficult to come to terms with the concept of having no treatment for an incurable cancer. With treatment often involving 'a watch and wait' strategy, people describe a growing sense of isolation, as increasing tiredness and lack of energy force a gradual withdrawal from work, hobbies and social activities.

*Chronic myeloid leukaemia* (CML) is a previously life-threatening illness that is now effectively managed with imatinib (Glivec), the ground-breaking new drug that was first trialled only in 1998 and has been licensed for less than 10 years. Some of those interviewed were among the first in the country to be treated with Glivec.

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At the other extreme *acute myeloid leukaemia* (AML) and *acute lymphoblastic leukaemia* (ALL) – most similar to childhood leukaemia - require urgent life-saving treatment with strong chemotherapies and sometimes other treatments, with long stays in hospital.

People with acute leukaemia describe putting normal family and work life on hold, sometimes leaving children with other family members. Many saw patients in the same ward dying from the disease that they had put behind them.

Most found returning to work a challenge and several changed job or retired, either because they couldn't cope with the demands of their previous lifestyle or because surviving had made them want to do other things with their life.

Quotes from patients illustrate the contrasting experiences of different types of leukaemia:

*"I think I expected to have to be rushed into hospital and have treatment straight away. It wasn't like that at all. He explained that the leukaemia I had was chronic lymphatic I think. It wasn't acute. It wasn't dangerous. It was something that would progress but it wouldn't necessarily kill me." Marilyn, 62*

*"They told me I'd be in hospital for six months and if I'm lucky I might come out for the odd night. So my kids went to live with my mum. I think that was the most devastating experience to me." Kerry, 32*

Senior Researcher Julie Evans, who led the project, said: "Despite my years of experience of researching other types of cancer, I had not realised how much I would learn.

"Leukaemia is not a single condition and trying to represent the huge range of experiences of acute and chronic leukaemias on Healthtalkonline has been challenging but immensely rewarding.

"I have been humbled by meeting and hearing the stories of people whose lives have been profoundly affected by leukaemia and am indebted to all the participants for so generously sharing their experiences to help others "

## The DIPEX Charity

DIPEX is a registered charity No: 1087019 and company limited by guarantee No. 4178865  
Registered office: 41 Cornmarket Street, Oxford OX1 3HA  
Co-Founders: Dr Ann McPherson CBE and Dr Andrew Herxheimer  
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## Note to editors:

### *About DIPEX/Healthtalkonline/Youthhealthtalk*

DIPEX has created two websites – [www.healthtalkonline.org](http://www.healthtalkonline.org) and [www.youthhealthtalk.org](http://www.youthhealthtalk.org) – of people’s experiences of more than 50 different illnesses and health conditions. The websites are aimed at patients, their carers, family and friends, doctors, nurses and other health professionals, and are based on in-depth qualitative research carried out by the Health Experiences Research Group at the University of Oxford.

Users of the websites will find accounts – presented through video, audio and written material – of issues such as reaction to diagnosis, consultation with their doctor, effect on work, social life and relationships, decisions on treatment options and side-effects. To date, [www.healthtalkonline.org](http://www.healthtalkonline.org) has covered illnesses including cancer, heart disease, neurological conditions (Parkinson’s, epilepsy and autism) chronic health issues (HIV, diabetes, rheumatoid arthritis) and mental health. We also provide experiences of women’s health, dying and bereavement. and publish young people’s experiences (including epilepsy, sexual health, teenage cancer) on our dedicated youth website – [www.youthhealthtalk.org](http://www.youthhealthtalk.org).

Supporters include Jon Snow, Dawn French, John Humphrys, Ian McEwan, Dr Jonathan Miller, Jenni Murray, Michael Palin, Philip Pullman, Libby Purves, Claire Rayner, Thom Yorke and many others. The actor, Hugh Grant has just agreed to be its patron.

DIPEX, a registered charity no. 1087019, is funded by the Department of Health and charitable trusts. Full details are on our websites.

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