



STRICTLY EMBARGOED until 00.01am on Sunday February 27, 2011

Ovarian Cancer Charity Offers Women Private Webpages to Share Their Thoughts and Feelings with Friends and Family.

Members of cancer charity Ovacome are now given their own secure blog page – called the Inner Circle – to communicate their personal emotions around their experiences of cancer.

The initiative was generated out of feedback from women diagnosed with ovarian cancer, that one of the hardest parts of living with the disease was managing the personal relationships with their closest friends and family. Having to do this via telephone and email to their network was described as “a big challenge”. The new technology has been designed to make it easier for friends and family to be informed and to provide emotional support where it is needed.

The software in the tool allows women to set up the page in a couple of minutes by listing the email addresses of their personal network, who are then alerted when there is a new update. They can then post their messages as a group.

The screenshot shows the 'Inner Circle' interface for a user named 'hastalapa'. It is divided into two main sections: a 'Post a journal entry' form and a 'Public view' of the entry.

Post a journal entry section:

- Step 1: Write your journal entry:** Includes fields for 'Title' and 'Body'. A note says 'Use your journal to share the highs and lows of your journey.' There is also a 'What should I write?' prompt.
- Step 2: Share with friends and family:** Includes a list of instructions: 'Enter the email addresses of the friends and family you'd like to notify.', 'Email address you enter here will be saved for next time.', and 'Put each email address on a new line. [Show example](#)'. There is a text area for sharing with groups.
- Did you know?:** A note states: 'Your Inner Circle is private. Unless you also share it with your groups, the email addresses in step 2 are the only way people can access your Inner Circle.'

Public view section:

- Title:** 'Feeling shaky' with 11 replies.
- Text:** 'Just a quick update today - first of all, thank you everybody for your lovely comments to our last blog about Flor's good news! He is floating about on Cloud 9. Strongly, I've been feeling really exhausted the last few days... because it's been the daily swimming class - I forgot! the fact that I'm not in the water! No, it's not been the swimming, it's the... makes me tired in a good way! I don't really admit to being nervous about going. Thankfully I got to see the psychologist at the Maggie's Centre again yesterday. She is really easy to talk to, and "Maggie" feels like a very safe space to really "feel" the feelings, especially the fear, that I am otherwise very good at "squashing" and putting out of my mind. My GP is very supportive too.'
- Replies:** A reply from 'Catherine' dated 25/02/2011 says: 'I'm beginning to really hit home that I'm not in the clear just yet. The idea that the fluid in my tummy means the disease is still active makes me so scared that I can't really hold onto it for very long. I think Flor's good news has helped me to feel positive again and been a great distraction! It was only yesterday that I really look on board properly what the gynaecologist told me on Monday. It's a balance I guess. I can't feel the fear all the time, but I have to keep it near me somehow and remember that things might still go either way. Hopefully everything will resolve itself and the fluid will turn out to be left over from my operation and MF treatment. If not, I guess I'll be more mentally prepared for having another operation if necessary. I certainly know my way around Newcastle! Including where to get the best tea and biscuits (in the Patients' Day Room)'. Another reply says: 'Someone said to me that uncertainty and waiting are worse than knowing something for sure. I don't really know about that, but I know that I'm looking forward to being back at work and contributing something again. Hopefully I'll keep my mind off my worries, too.'
- Annotations:** Four callout boxes point to specific features:
 - 'Women post an update with news of their Ovarian Cancer here.' points to the user's profile and title.
 - 'The update appears as a blog that can only be accessed by the Inner Circle of friends and family' points to the main text area.
 - 'They add emails and addresses of their friends and family here' points to the 'Share with friends and family' section.
 - 'Friends and family can post messages of support here' points to the replies section.

The secure webpage is designed to provide a private place to communicate solely about a sensitive subject such as ovarian cancer, in place of the more public platforms such as Facebook for this issue.

One user, Catherine Hollebrandse, 33, who was diagnosed with ovarian cancer in July 2010 said : “I have been on a rollercoaster since my diagnosis - everything has happened so quickly. The online blog has been a godsend, like an online diary that I can record both medical appointments and information in, and also express how I’m feeling emotionally.

“Writing everything down in one go and sharing it with those close to me means I don’t have tell them each individually. Telephone conversations can be very upsetting and emotionally draining. Now when I talk to them, they already know what is going on with my health, so we can talk about more light-hearted things.”

Louise Bayne, chief executive of Ovacome, says: "Talking about a cancer diagnosis and the highs and lows of treatment can be a real challenge. The inner circle is proving a fantastic tool for sharing information and receiving much needed support in a way that suits the individual without being obtrusive. It is helping to overcome many of the barriers to supportive communication that exist, and we are proud to be the first cancer charity in the UK to offer this service."

Matt Jameson Evans of HealthUnlocked (the UK health technology company who provided the system for free to Ovacome) said: "We are delighted that this platform has met a particular need for those women facing a cancer diagnosis. We hope to offer the service to other Cancer charities in 2011, as clearly the communication difficulties are not confined to ovarian cancer alone."

-ENDS-

Editor's Notes

Ovacome, the ovarian cancer support and information network, which has over 5,500 members, is working to support both women and health professionals to improve the diagnosis of the disease. The charity is leading the way in building a greater understanding of the disease's symptoms with the launch of its BEAT campaign in March 2010. As part of this GP involved initiative, Ovacome has introduced an innovative web-based risk and symptoms toolkit for women who suspect that they may have the disease to mark Ovarian Cancer Awareness Month in March 2011.

Ovacome, which has its own nurse-led support service, has an unrivalled understanding of ovarian cancer and the clinical trial process, with access to the UK's top clinicians.

It prides itself on being the authority on the disease and the one stop shop for journalists wanting the latest information and statistics on ovarian cancer, as well media-friendly case studies and photos.

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