

The Missyou website

Run by hospices for hospices, Missyou – www.missyou.org.uk – is the only site of its kind provided by bereavement professionals who deal with grieving friends and families on a daily basis. Missyou allows visitors to easily create an individualised ‘tribute’ page online. Users are able to write a biography of a loved one; share stories, memories and thoughts. Visitors are also able to upload and share photographs with others, they can create a ‘life and times’ history of the person they are remembering and light a virtual candle in memory. Via the website, users can tell friends and family about the tribute web page and invite them to leave messages, stories and memories; and give a gift in memory to a hospice on a special day or anniversary should they wish to.

Missyou was created and developed by Weston Hospicecare in Weston-super-Mare. They identified that supporters were still visiting and posting messages and memories online, many months after a Christmas service had offered them the opportunity to do so. They realised that there was a real need for something that could offer this kind of service throughout the year, not just at Christmas.

Weston Hospicecare then approached Help the Hospices and proposed working in partnership to make Missyou available to hospices across the country. At the time of going to press, there were 15 hospices across the UK working with Missyou and it had attracted significant attention from national press and radio.

David Burland is Director of Income Generation at Help the Hospices, and he has explained the significance of the site coming from a hospice, rather

than from a commercial organisation. He says, ‘What makes the site unique is that from the start, Weston fully involved their clinical and care staff, including their chaplain, medical director, and bereavement services manager, ensuring it is a place which hospices can feel confident in offering families and friends. We immediately thought it was a great idea.

People are thinking of different ways to remember people and this is what the internet is good at. It offers an interactive way for people to come together and celebrate the life of someone who was special to them. We are not saying this is for everyone but it’s there if people want to use it.’

Weston Hospicecare, and the other hospices using the service, have recognised that there are a number of benefits to using the website. The site adds to the support services that hospices already offer to grieving families and friends, in a contemporary and relevant manner that has a global reach. Importantly, visits to the tribute site can be restricted to chosen members of the family or published online for all to see – and, in either case, requires a secure password to add thoughts and memories. It can be accessed alone, in times of quiet contemplation, or with others to share memories and photographs. It can help celebrate that person in their happier days, rather than with illness and distress, images which often are hard to forget.

Many of the users we’ve spoken to talk very eloquently of the site. They see it as a safe place to be, a place where they can feel free to express emotion. Alan Wigmore lost his wife 18 months ago and has used the site, which has given him a chance to pay tribute to her. ‘You don’t have to look your best and it

doesn’t matter what time it is,’ he said. ‘It just gives you some peace. I feel she is closer to me when I am on the site’ ■

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Improving quality of life: Bach flower remedies in hospices

In our experience, as three Italian Bach flower practitioners registered at the Bach Foundation and one naturopath, we have had the opportunity to realise that Bach remedies are not currently used in Italian hospices and palliative care services. We are convinced that Bach flower remedies can provide easy and natural help towards balancing negative emotions and improving the quality of life of patients as well as their relatives. They do not present either contraindications or interactions with medical therapies.

We have, therefore, decided to propose to the Italian hospices and palliative care structures the use of the Rescue Remedy – the remedy for first aid use and stress management – and then, if successful, to train some members of the team to use the Bach flower remedies (Level 1 official training of the Dr E Bach Foundation).

We would also provide support and counselling. We think it is essential to gather and divulge some results of what has been successfully implemented abroad, so that the project can be sustained with more documentation.

We have already found that Bach flower remedies are actually in use in hospices and palliative care settings in these countries in the UK, Norway, the USA, Australia and Italy. We would be very grateful if you could provide us

with information about similar trials in services or hospitals already using Bach Flower Remedies in palliative care around the world ■

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The EPCRC

Based on the EAPC Research Network, an extended research collaborative has been established within the palliative care community in Europe. The European Palliative Care Research Collaborative (EPCRC) consists of eight participating centres in six European countries: the UK (King's College, London, Bristol Haematology and Oncology Centre, and the University of Edinburgh), Italy (Fondazione IRCCS Istituto Nazionale dei Tumori, Milan), Switzerland (Cantonal Hospital, St Gallen), Germany (University Hospital Aachen), Austria (the Medical University of Graz and Bender Med Systems GmbH, Vienna), and Norway (Norwegian University of Science and Technology [NTNU] and Trollhetta AS, Trondheim).

Co-ordinated by the Pain and Palliation Research Group in Trondheim, the collaborative's proposal was successfully evaluated in 2006 and received a 2.8 million Euro funding from the European Commission for a three-year period, starting from 1 November 2006.

Research areas

The research areas for the project were determined by the European Commission. The work concentrates on three major symptoms: pain, depression, and cachexia. Control of these symptoms is pivotal for the quality

of life of millions of palliative care patients. Pain is one of the most common problems and the most feared symptoms. Although there are several publications on the classification of pain, there is still no international consensus on how to assess or measure it. The prevalence of depression varies from six to 58% in palliative care patients, reflecting the lack of standardised validated methodology for its assessment in this patient group.

Cachexia is likely to be the most important contributor to fatigue in advanced disease. Nevertheless, there is no agreed classification system or diagnostic approach to this condition. Improving the management of these conditions in cancer patients demands new knowledge through research in several areas.

The research plan of the EPCRC addresses questions raised in the clinical setting by a multidisciplinary translational approach in which basic scientists and clinicians will combine human genome data, results from systematic literature reviews and data from clinical studies into practical applications for palliative care patients. Assessment and classification of pain, depression and cachexia are the basis for diagnosis and subsequent treatment. By use of modern methods of molecular biology the EPCRC will increase the understanding of the role of genetic variability. European evidence-based internet guidelines will be developed.

Aims of the project

The overall objectives of the EPCRC are to develop novel genetic methods for prediction of opioid responses and individual variation of cachexia, methods for assessment and classification of pain, cachexia, and depression, and clinical guidelines for assessment and treatment of these three symptoms/conditions.

The aims of the project may be listed as follows.

- To identify genes and genetic variation relevant for inter-individual

variation in opioid responses and genetic variation that may identify patients at particular risk of developing cachexia.

- To improve classification and assessment of pain, depression and cachexia by computer-assisted approaches.
- To combine the new knowledge of symptoms, genomics and assessment in an internet-based system for implementation of European evidence-based guidelines, which will include standardised assessment and individualised treatment plans for pain, depression and cachexia.
- To develop a long-lasting European collaborative in palliative care cancer research.

Conditions for success

The work within the EPCRC is divided into five major work packages involving between 50 and 60 researchers. Expert groups have been formed, with members from inside and outside the collaborative. The collaborative clearly has the opinion that this work is performed on behalf of the entire palliative care community in Europe, aiming at practical results to influence and improve patient management in daily clinical practice. To reach this aim, the collaborative is highly dependent on broad input and feedback from the palliative care community.

EAPC conferences and research forums provide excellent opportunities for workshops and discussions and will be used to this end. The EPCRC is organising three workshops during the Budapest conference, and we hope that there will be active participation from a wide range of palliative care practitioners. The EPCRC website (www.epcrc.org) provides information about all parts of the project as well as options for discussion and feedback ■

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