



It's about living not just surviving

→ Kathy Redmond ■ EDITOR

Patients are living with advanced cancer for ever more prolonged periods of time. But information and support services have been slow to catch up with clinical progress, and the needs of this rapidly growing group of patients are not being met.

All too frequently, information is targeted solely at patients with early disease, and fails to address issues such as disease progression, treatment options, symptom control and end-of-life care. Lack of support is also a problem, leaving many patients feeling terribly isolated. A recent survey of patients with metastatic breast cancer showed that patients often find it very difficult to talk openly about their condition, even with close family and friends.

For patients with advanced disease, who have to face the hard reality of running out of treatment options, joining a clinical trial could be their only hope. Yet many are still not getting information about trials they may be eligible for when their disease starts to progress – ironic given that this group of patient is often the most enthusiastic about participating in trials.

The fact that patients with advanced cancer are often excluded from trials on the grounds that they have certain types of metastases or have simply undergone too much pre-treatment only compounds the problem. Compassionate use programmes offer a potential solu-

tion for some patients, but many find this option is blocked by various obstacles, including the diverse bureaucratic rules governing these programmes in many European countries.

The European Commission recently took a step in the right direction with new guidelines about the type of information that should be made publicly available on the EU medicines database EudraPharm (www.eudrapharm.eu). Patients should now be able to search for information on all ongoing phase II, III and IV trials in the EU, regardless of whether or not the medicine under investigation is approved.

More progress is urgently needed, however, to help those with metastatic disease live life to the full and continue to make a valuable contribution to society.

It is high time we started investing in the development of tailored support and information services that can promote health and wellbeing in this population. We should identify and address barriers to clinical trial participation and help patients gain access to promising innovative medicines.

Above all, we should challenge the myths and misconceptions that present advanced cancer as a necessarily bleak and miserable journey of doom, and spread the word that it is often possible to live an active and satisfying life for a long time – particularly with the help of effective support systems.