

Out of the shadows

There is an urgent need to bring brain tumours and other rare and less common cancers into the light, says **Kathy Oliver**



It is a place often cloaked in half light and shadows – the relatively uncharted corners of the cancer map. Turn left just after the “Big Four” of breast, lung, prostate and colorectal. Travel along a rocky, isolated terrain to the forest where money certainly doesn’t grow on trees. Take another left, then a right and continue on to an arid region, desperately crying out for the rain of more research and the sunshine of hope. And there you have it – the place where rare and less common cancers dwell. It is a landscape in turmoil.

A desperate lack of funding for research; inequity in accessing promising new therapies, misdiagnosis and late diagnosis; a paucity of specialists and specialist centres, incomplete registries – these are just some of the problems encountered with the rare and less common cancers.

Governments, as well as major international and national cancer control organisations, have prioritised prevention, screening and healthy living campaigns in the fight against cancer. These are all excellent initiatives. But not every cancer can be helped by this approach. The worry for those living with a rare or less common cancer is that the focus on prevention, screening and lifestyle options may displace the equally important activities of research, awareness raising, support and advocacy.

Take the example of brain tumours. This devastating disease can affect a person’s cognitive, emotional and physical abilities. A brain tumour strikes at the very core of one’s being. It can affect everything that makes that person who he or she is. Despite some advances in treatment over the last few decades, brain tumours remain one of the most lethal,

most challenging of cancers. While brain tumours are not a major cancer in terms of incidence they shoot high up the list in terms of “average years of life lost” which is a measure of the burden of cancer to the individual patient.

Prevention? The causes of most primary brain tumours are largely unknown. For instance, despite continuing controversy and numerous studies, there appears to be no agreed firm evidence yet that mobile phones cause brain tumours. Without knowing their causes, there can be no prevention programmes for brain tumours.

Screening? Brain tumours do not discriminate by sex, race, geography, religion, class or age. They mostly appear to attack at random. Universal screening for brain tumours is unrealistic. **Lifestyle options?** Anti-smoking campaigns surely save more lives from lung cancer. Weight control and healthy eating might also help cut some cancer deaths. But there appears to be no such lifestyle shift to avoid a brain tumour.

So we must now ask: “What is being done for the rare and less common cancers, like brain tumours, which are stubborn, intractable and which are not affected by prevention, screening and lifestyle programmes?” There is an urgent need to bring brain tumours, and indeed other rare and less common cancers, out of the shadows on the cancer map, and to put them on the political and cancer control organisation agendas.

A coalition of over 30 rare and less common cancer groups in the UK called “Cancer 52” (so named because 52 per cent of cancer mortality is due to rare and less common cancers) has recently helped to raise their profile by participating in the UK department of health’s cancer reform strategy consultation.

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On February 29th – cleverly chosen to fall on the leap year’s rare date – the European organisation for rare diseases (EURORDIS) is spearheading the inaugural “European rare disease day” which will further highlight the plight of people affected in this way. In addressing the challenges of the rare and less common cancers, we must be careful to ensure that the road signs do not only point to prevention, screening and lifestyle options.

Brain tumour patients and other rare and less common cancer sufferers – for whom there has been far too little for far too long – must travel a different path. This path should lead to increased government funding into the development of cutting edge therapies; as well as greater public awareness; additional support and determined advocacy.

We very much hope that the commission communication on rare diseases, expected in 2008, will shine a bright light into the darkness. It’s time for brain tumours and other rare and less common cancers to emerge from the shadows. ★



Kathy Oliver is secretary of the international brain tumour alliance (IBTA)