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**Searching for an Anchorage in an
“Unmoored State” How Can Patients
with Brain Metastases Be Helped by
Brain Tumour Patient Advocacy and
Support Organisations?**

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Searching for an Anchorage in an “Unmoored State” How Can Patients with Brain Metastases Be Helped by Brain Tumour Patient Advocacy and Support Organisations?

Kathy Oliver

In his fascinating “biography of cancer”, *The Emperor of All Maladies*, author and Pulitzer Prize winner Dr Siddhartha Mukherjee quotes the 20th-century American surgeon William Bainbridge who wrote: “Throughout the centuries the sufferer from this disease has been the subject of almost every conceivable form of experimentation. The fields and forests, the apothecary shop and the temple have been ransacked for some successful means of relief from this intractable malady. Hardly any animal has escaped making its contribution, in hair or hide, tooth or toenail, thymus or thyroid, liver or spleen, in the vain search by man for a means of relief” [1].

As patients, caregivers, researchers, medical professionals, academics, and representatives of industry, we desperately search for that “means of relief” from cancer in all its devastating forms, whether common or rare, primary or metastatic.

Mukherjee also quotes the American surgeon-writer Sherwin Nuland who described the cancer cell as “*a desperate individualist*” and “*in every possible sense, a nonconformist*” [1].

Mukherjee goes on to say, “*The word metastases, used to describe the migration of cancer from one site to another, is a curious mix of meta and stasis – ‘beyond stillness’ in Latin – an unmoored, partially unstable state*” [1].

■ The Default Support and Information System

Many of the symptoms of metastatic brain tumours, as well as the physical and emotional impact from them, are similar to those of primary brain tumours.

But where would a person turn for information and support when first diagnosed with a metastatic brain tumour?

For example, if they lived in the UK and had brain metastases from lung cancer, would they immediately phone the Roy Castle Lung Cancer Foundation, or would they phone The Brain Tumour Charity? If they lived in Canada and had brain metastases from kidney cancer, would they contact Kidney Cancer Canada or Brain Tumour Foundation of Canada? If they lived in Belgium and were diagnosed with brain metastases from breast cancer, would they get in touch with the breast cancer charity Europa Donna or Werkgroep hersentumoren – the Belgian brain tumour association?

Sarah Lindsell, Chief Executive of The Brain Tumour Charity (UK), said, “*Having looked at our figures for the first 6*

months of the year, I can see that only 5 of the individuals who contacted us did so in relation to a secondary tumour. This represents less than 1 % of all our enquiries. Furthermore, looking at our online support presence we are not aware of anyone who accesses support in this way for a secondary brain tumour. When we do receive such contacts, emotional support is provided in the same way as we would support someone with a primary brain tumour. Information is given in relation to the nature of secondary tumours and ... in relation to possible treatments such as stereotactic radiosurgery (SRS) and whole brain radiotherapy (WBRT).”

She added, “*... people who have a secondary brain tumour are often already receiving support from charities who supported them through their [original] cancer diagnosis and treatment of the primary tumour site ...*” [2].

Patient advocacy colleagues in the European and North American kidney cancer community have also confirmed to us that their patients generally default to their primary diagnosis support and information systems at kidney cancer organisations rather than necessarily contacting a brain tumour patient organisation [3].

Based on anecdotal evidence such as this, it would appear that patients diagnosed with metastases to the brain think of themselves as breast cancer patients with metastatic disease; kidney cancer patients with metastatic disease; lung cancer patients with metastatic disease, etc, and not necessarily brain tumour patients. Patients may also identify themselves as having “advanced cancer” which may well not elicit the same horror and stigma as the term “metastases to the brain”.

Nevertheless, this is not to say that brain tumour patient organisations are irrelevant regarding metastatic brain tumour patients. Far from it. They can provide much-needed information and support and fulfil the advocacy role in a similar way that they do for primary brain tumour patients.

■ Seeking Information – A Predominant Theme

In a paper published in *NeuroOncology* in 2006 by Jane Schubart et al, “Caring for the Brain Tumour Patient: Family Caregiver Burden and Unmet Needs”, the authors suggest that information-seeking has emerged as a distinctly predominant theme during this devastating journey. The authors note: “*The research on information needs and chronic illness suggests that almost all cancer patients want to be fully informed about*

the various aspects of their disease and treatment and, in increasing numbers, are assuming a proactive role in their own care.

A growing body of research finds that when patients and families have a better understanding of their diagnosis and treatment, they are more able to cope with their problems, use the health system more effectively, and have less psychological distress. Improved coping strategies, in turn, generally result in better adjustment to a cancer diagnosis” [4].

There is a very important role for brain tumour patient organisations in helping people with brain metastases. This does not involve replacing a patient’s connection with his or her primary cancer site support network. Instead it means forging new partnerships and collaborative initiatives between brain tumour and other site-specific cancer patient organisations to ensure that people with metastatic brain tumours receive the most comprehensive information available.

■ Sharing Support

On the support front, every metastatic brain tumour patient should be given a “systems navigator”. This could be a specialist neuro-oncology nurse, a social worker, or other trained person who can signpost relevant support groups, facilitate access to social welfare payments/services, and assist with access to specialist support, ie, physical therapy, psychosocial support, and help in dealing with side effects like epilepsy and fatigue.

Again, brain tumour patient organisations can become involved by working in partnership with primary cancer site patient organisations and provide assistance with support groups specifically for metastatic patients, dedicated telephone helplines, and maintaining morale.

Coping with uncertainty and a reduced life expectancy; the need for practical support and help in returning to pre-treatment responsibilities or preparing for longer-term care; overcoming social isolation, stigma, and discrimination are some of the major themes identified by Monika Janda et al relating to the supportive care needs of patients with primary brain tumours and their carers [5]. These themes may also be relevant for those suffering from brain metastases.

Brain tumour patient organisations already have substantial experience in understanding and delivering support for primary brain tumour patients. By collaborating with other site-specific cancer patient organisations, we can share our experiences so that secondary brain tumour patients can also benefit and get the support they need.

■ Patient Advocacy Brings Change

The National Cancer Institute (NCI) defines cancer advocacy groups as organisations which “*try to raise public awareness about important cancer issues, such as the need for cancer support services, education and research. Such groups work to bring about change that will help cancer patients and their families*” [6].

In a paper on patient advocacy by Melissa Gilkey and JoAnne Earp, the authors say that “*a specific definition of patient advocacy is difficult to articulate, in part because the term has been used in many different ways*”. But they say that the concept of patient advocacy “*generally refers to efforts to support patients and their interests within the context of the health care system*” [7].

Whether we come from brain tumour organisations or those dealing with kidney cancer, bowel cancer, melanoma, lung cancer, or breast cancer, we all have the same goal in mind – to help improve the situation for our patients and to provide them with the best, most hopeful, and comfortable journey possible.

There are numerous issues affecting metastatic brain tumour patients which could be addressed through advocacy efforts by brain tumour patient organisations working collaboratively with primary cancer site organisations to put pressure on governments, regulators, and health authorities.

■ Advocacy Issues and a Force for Change

First, every metastatic brain tumour patient should be assigned to a multi-disciplinary team (MDT) just as primary brain tumour patients are. All treating centres for brain metastases should have appropriate MDT pathways and the correct capacity to ensure that brain metastases patients are treated quickly and optimally.

Second, where national or international guidelines exist to treat metastatic brain tumour patients – and there are a number of these already in place (see reference list) – are they being adhered to on a regional or local level? If not, why not? [8, 9].

Third, if stereotactic radiosurgery (SRS) is appropriate, are the waiting times on national health services for accessing this treatment acceptable? If SRS is not available in a particular region or country, how can this situation be changed/improved?

Fourth, in these cash-strapped times who will fund research into metastatic disease? Will members of the public – who currently provide a large percentage of brain tumour research funding through donations to brain tumour charities in different countries – continue to do so in these economically challenging times?

And finally, do statistics about brain metastases need to be quantified more accurately so that we can better identify service, treatment, and support requirements? How can we efficiently serve a community of metastatic brain tumour patients when we do not even know how many of those there really are? How can we budget for their needs?

Patient advocates can help address all of these challenges and more by being a force for change. We can put pressure on governments, regulators, industry, and the healthcare sector to achieve improvements in access to treatments and support because even in the richest and most powerful countries on

this planet, patients can be lost in a maze of uneven and inequitable care.

Brain tumour patient groups are crucial in ensuring that people with brain tumours – whether they are primary or metastatic – are treated equally and have every opportunity to access the highest possible level of care and support.

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