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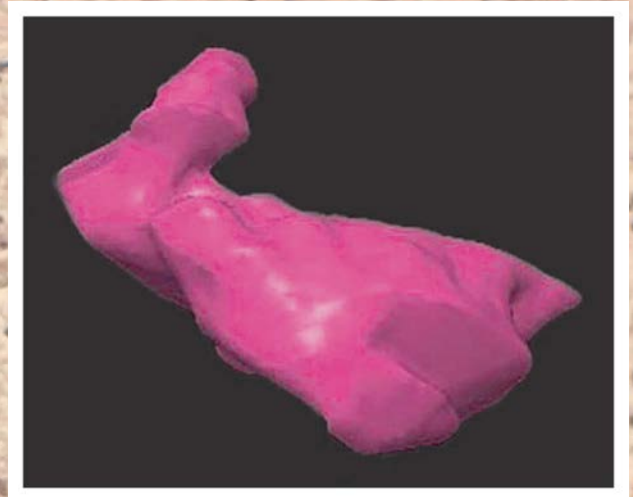
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The Role and Support of Caregivers: We Also Ride the Brain Tumour Roller Coaster

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The Role and Support of Caregivers: We Also Ride the Brain Tumour Roller Coaster

Kathy Oliver

"It's like standing on the shore watching him out at sea. Sometimes the waves bring him back closer to me and sometimes the tide takes him away again."

These words, written by a caregiver, hauntingly capture the emotional ups and downs of looking after a person with a malignant brain tumour. Brimming with pathos, tinged with strain, and symbolic of a journey that is unique in the atlas of diseases, these 2 simple sentences highlight the fact that caregivers also ride the brain tumour roller coaster.

One of the most striking things about brain tumours is that, unlike other cancers, they intersect 3 major disease areas: cancer, neurological disease, and rare disease. This triumvirate presents a huge challenge to both the patient and the caregiver.

■ Understanding the Caregiver's Perspective

The stresses resulting from a brain tumour diagnosis are significant and fairly well-documented for patients. But the effects of this devastating diagnosis on the caregiver were historically not so widely understood or recognised.

In recent years, however, there have been a number of studies focussing on the brain tumour caregiver's role, especially with regard to high-grade glioma.

A team from the Department of Oncology at the University Hospital in Leuven, Belgium, led by Wendy Sterckx, carried out a systematic review from the patient's and caregiver's perspectives on the impact of a high-grade glioma on everyday life. The results were published in the *European Journal of Oncology* in 2012 [1]. The review states:

"Caregivers associate the diagnosis [of a brain tumour] with a loss of safety in daily life. Suffering and powerlessness loom large ... Feelings of being overwhelmed, denial, anger and isolation are described. In an attempt to cope with the diagnosis, caregivers take every day as it comes and do not want to plan ahead. They try to prepare themselves for the worst and want to be ready for when the patient deteriorates."

This same Leuven review mentions that the patient's cognitive and neuropsychiatric symptoms are the greatest challenges for caregivers.

Furthermore, the paper quotes other studies – notably Fox and Lantz, Sherwood et al, Janda et al, and Schubart et al – when it reports:

"[A brain tumour] is a family disease. Caregivers' distress is reflected in burden and depressive symptoms, both related to the reduced independence and neuro-psychiatric symptoms of the patient. Compared with caregivers of other brain tumour patients, caregivers of patients with a glioblastoma have a worse quality of life and may have more psychosocial needs because the disease process is faster and they have less time to adapt."

A 2010 Australian study of high-grade glioma brain tumour caregivers from a team in Perth pointed out that:

"... Caregivers in this study reported experiences similar to those described by caregivers of people with other cancers. What differed for this group [of brain tumour caregivers] was the rapidity of change and the need for immediate information and support to assist with caring for a person with high grade glioma" [2].

■ Living the New Normal

After diagnosis, brain tumour patients and their caregivers must try to rebuild their lives and learn to live the "new normal".

For the caregiver this may include a major readjustment in family dynamics and roles. Caregivers may have to learn how to move and handle a patient, organise equipment, monitor and administer medications, become the family's main transport person, oversee the patient's personal care, and help the patient cope with treatment side effects.

Caregiving can be incredibly intense and extremely isolating. On the other hand, many caregivers have also said that the inspiration and courage shown by the brain tumour patient may bring them to a new level of deep love, admiration, and closeness with the patient. Time together is cherished in a way that it has never been before.

■ Caregivers and the IBTA Survey

The International Brain Tumour Alliance (IBTA) carried out a patient and caregiver satisfaction survey in 2010 which asked: "Was information about your diagnosis and prognosis provided to you in a considerate and sensitive manner and in a suitable physical environment?" [3].

Although 59 % of those surveyed responded "yes", a number highlighted less than satisfactory situations. They included a lack of compassion shown by medical staff, bad news being broken in inappropriate surroundings, and a nihilistic attitude on the part of doctors.

One respondent wrote:

"We did not understand the terminal prognosis, it was not properly explained ... [This was] harmful to the surviving partner as expectations were not properly set. The surviving partner is a 'patient' in this sense also, but is not treated as such. I think there is a need for counselling being given to the partner-carer in parallel with the treatment for the patient."

■ Helping Caregivers Cope

So what can caregivers do to help themselves cope on this journey?

Information, befriending, and support for caregivers is available from brain tumour charities. However, not every country is fortunate enough to have these organisations. A directory of brain tumour charities known to the IBTA is available at

www.theibta.org/websitelinks.html

A 2012 article in *Brain Tumour* magazine by Dr Martin Klein of the VU University Medical Center in Amsterdam says:

"Research to date indicates that, while continuing to face significant caregiving stress, caregivers can benefit greatly from structured psychosocial interventions, leading to clinically significant improvements in the caregiver's quality of life."

We at the IBTA have seen that it may be useful for families, if they wish, to be paired in a buddy system with other families on the same journey so there is peer-to-peer support. This is something that brain tumour patient support groups often facilitate. But unfortunately, not all families are put in touch with these groups by clinicians at the time of diagnosis.

Some neuro-oncology departments run their own support group meetings which facilitate such introductions. In many cases, it is the specialist neuro-oncology nurses who run these groups.

Klein also mentions the use of

"... E-Communities by which caregivers are connected to their peers ... over the Internet."

There are, in fact, a number of highly regarded, reliable web resources for brain tumour caregivers.

Used by patients and caregivers worldwide, the US-based Musella Foundation's website – www.virtualtrials.com – houses a section on survivors' stories which can help give people hope. The website also hosts a number of excellent

online discussion groups where patients and caregivers can find information, support, friendship, and understanding.

The Cancer Institute New South Wales (Australia) website features an excellent set of 16 brain tumour fact sheets and 11 resource sheets. These cover topics such as anger management, stress, concentration, communication, and fatigue, and are not just aimed at the brain tumour patient but at the caregiver as well.

■ Lessons Learned

There is no exact science to caregiving. It seems to hover somewhere between treading on eggshells, juggling dozens of balls at once, and having unlimited reservoirs of physical and mental strength.

As one of the caregivers to our son Colin for over 7 years, until he died in August 2011 from his brain tumour, I learned many lessons.

I learned that caregiving must be a partnership so that the patient can make his or her own decisions and choices as much as possible in order to feel that they are still in control.

I learned that it is also vital not to forget the needs of other people in the family; to accept help from relatives, friends, and neighbours when they offer it; to maintain continuity and as much of a sense of normality as possible.

Finally, I learned that the hope and encouragement you give as a caregiver to the patient can go a long way in helping alleviate some of the nightmarish aspects of the brain tumour journey. As Dr Jerome Groopman, a leading cancer researcher, said:

"Hope acknowledges the significant obstacles and deep pitfalls along that path. True hope has no room for delusion. ... Hope gives us the courage to confront our circumstances and the capacity to surmount them" [4].

Notes:

1. Sterckx W, Coolbrandt A, Dierckx de Casterlé B, et al. The impact of a high-grade glioma on everyday life: a systematic review from the patient and caregiver perspective. *Eur J Oncol Nurs* 2013; 17: 107–17.
2. McConigley R, Halkett G, Lobb E, et al. Caring for someone with high-grade glioma: a

time of rapid change for caregivers. *Palliat Med* 2010; 24: 473–9.

3. Klein M. Caregiver burden in relation to a brain tumour diagnosis. *Brain Tumour* 2012; 58–9.

4. Groopman J. The anatomy of hope. Random House, New York, 2004.

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