

European Association of NeuroOncology Magazine

Neurology · Neurosurgery · Medical Oncology · Radiotherapy · Paediatric Neuro-
oncology · Neuropathology · Neuroradiology · Neuroimaging · Nursing · Patient Issues

Caring for Patients and Their Carers

Zwinkels H

European Association of

NeuroOncology Magazine 2012; 2 (2)

97

Homepage:

[www.kup.at/
journals/eano/index.html](http://www.kup.at/journals/eano/index.html)

Online Database Featuring
Author, Key Word and
Full-Text Search



THE EUROPEAN ASSOCIATION OF
NEUROONCOLOGY

Member of the 

Caring for Patients and Their Carers

Hanneke Zwinkels

For the second time, in the Netherlands a National Brain Tumour day was held on March 17, 2012, and I was invited to speak about “Caring for patients and their carers”. The programme contained presentations of physicians representing the multidisciplinary character of diagnosis and treatment of brain tumour patients as well as a contribution of a patient. In the afternoon, there were sessions in smaller groups with experts, patients, and their carers, addressing various topics such as new treatment modalities, clinical research, and psychosocial care. I would like to share with you what I discussed with the audience consisting of patients, their carers, and brain tumour survivors.

When there is suspicion of a brain tumour the patient and his or her carer meet difficult times of uncertainty and challenges, in awaiting the definitive diagnosis and possible treatment of the brain tumour after resection or biopsy. There is fear of hearing the worst news in a lifetime and there is hope. Hope that treatment will be possible, hope for rehabilitation, hope for a favourable outcome. And if treatment is necessary there is hope to be able to endure treatment, for good results, for an MRI with no signs of tumour, for quality of life. But anxiety and uncertainty remain.

In academic and other neuro-oncology centres in the Netherlands, specialized oncology nurses are part of the multidisciplinary team, available to deliver psychosocial care with a low threshold. Patients and their carers can call or e-mail or just drop by with a question, to help diminish or eliminate anxiety or to talk about experiences in the process of the disease. As part of the multidisciplinary team, the neuro-oncology nurse offers help and guidance throughout the process of the disease and its treatment. During contacts at the outpatient clinic, besides talking about treatment and MRI results, often other subjects are addressed: how to get help in managing difficulties such as hemiparesis, aphasia, and hemianopia; how to cope with personality and character changes such as egocentricity, agitation, inappropriate or impulsive behaviour, lack of insight, loss of initiative, fear, anxiety, depression; practical subjects, such as driving and getting help and support for housekeeping, support within the family, with children, help to discuss the disease and its impact even at school; help and referrals for rehabilitation, adjustments at home, help in taking care of the patient, day and night, help for the carer in taking care for him- or herself. Furthermore, there is the problem of fatigue, addressed by talking about ways of prioritizing activities and being able to maintain contacts. Another subject of dialogue can consist of existential issues and questions, neuro-oncology nurses want to create openness for the patient to be able to talk about the end-of-life phase, and by doing that they hope to take away anxiety and uncertainty.

Having heard the “bad news”, patients often cannot hear, remember, or comprehend what is being said about treatment. What they do remember is that the doctor told them that they will eventually die of their brain tumour. David Bailey was diagnosed with a glioblastoma and survived for 13 years after his initial diagnosis. He advocated giving patients hope so that they would be able to cope in their fight against their brain tumour. I try to give my patients examples of brain tumour patients such as David Bailey, who lived for a long time after diagnosis with good quality of life.

It helps them because it gives hope and faith in being able to endure treatment “to beat the brain tumour.”

Patients and their partners have to be able to adjust to the situation of having to deal with a disease, its treatment, signs, and symptoms. They need to be able to set achievable targets, to discuss their problems and, if possible, to find a way to resolve problems. It will help patients to be able to be directive, to have the feeling of control, to manage their lives with the disease. What also attributes to self control is to receive honest information, if necessary, good psychosocial care, and referrals to get the right help at the right time and at the right place. Much information is available at the internet, at web portals of hospitals, of patient support groups, of associations, and societies involved in brain tumour treatment. Relatives will help seek the best hospital, the best doctor, and the best treatment. Some of those treatments will give hope, but others will perhaps give false hope. Some patients state that, “What you don’t know cannot hurt you”, but the question I would like to ask is, “Is all the information found on the internet reliable, comprehensible, and is it possible to translate this to the specific situation of an individual patient?” You could ask yourself what you do want to know and at what time you do want to know.

I have learned from a book I received, written by a patient with a brain tumour treated in The Hague, that not knowing and being able to live her life without constantly being confronted with the possibility that the tumour will recur at some time was her way of having control over her illness. She – a psychology student – was accidentally diagnosed with a low-grade glioma which dedifferentiated a year after the initial diagnosis and she passed away within 4 years. Her diary gives insight into how she coped with her disease and taught me that it is very important for a brain tumour patient to be able to create hope. Besides, I learned that being a neuro-oncology nurse I am not responsible for the disease but I am responsible for the way I inform, guide, and care for the patient.

What if it is no longer possible to hope for cure, if there is no longer the possibility for treatment of the tumour? Then I am responsible for trying to create hope for a chance of being able to set achievable goals, a chance of fulfilling tasks and unfinished business, of doing what is worthwhile to do, of being open about what to expect of the end-of-life phase, create hope that the patient will be able to live his life the way he wants until it is time to say good-bye.

Further Reading:

Catt S, Chalmers A, Fallowfield L. Psycho-social and supportive-care needs in high-grade glioma. *Lancet Oncol* 2008; 9: 884–91.
Fleming J, O’Gorman A. High-grade brain tumours: managing symptoms from diagnosis to

terminal phase. *Eur J Palliat Care* 2011; 18: 6–9.

Salander P, Bergenheim T, Henriksson R. The creation of protection and hope in patients with malignant brain tumours. *Soc Sci Med* 1996; 42: 985–96.

Correspondence to:

Hanneke Zwinkels, RN, MA ANP
Medical Center Haaglanden
PO Box 432, NL-2501CK The Hague
e-mail: hannekezwinkels@eano.eu