



Oncology Center Antwerp
Lange Gasthuisstraat 45, B-2000 Antwerp

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**CONSENSUS ROUND TABLE ABOUT TREATMENT AND SUPPORT OF
BRAIN TUMOUR PATIENTS AND THEIR FAMILIES**

POLICY NOTE

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1. Scope of the Round Table

The Round Table presents a consensus between all actors involved with Brain tumours and to health and welfare authorities.

The term “Brain tumours” has to be understood as “Tumours of the Central Nervous System” according to the classification of the WHO.

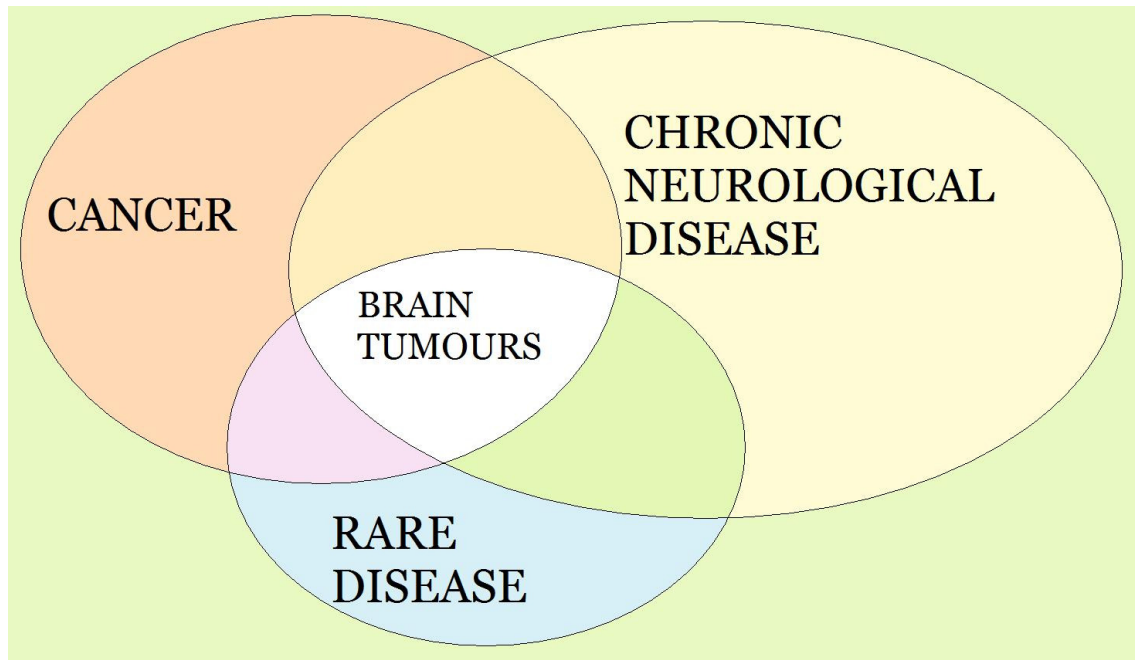
The starting point is the European “Council Recommendation on Action in the Field of Rare Diseases” of 08.06.2009¹.

The goal is to achieve:

1. An optimal quality of treatment.
2. A good access to quality care based on expertise about brain deficits.
3. Continuity in the patient trajectory.

¹ Council recommendation of 8 june 2009 on an action in the field of rare diseases, ,2009/C 151/02

2. Situation of Brain tumours



Brain Tumours are:

- **A kind of cancer with a very high mortality.** The incidence for all tumours of the central nervous system in Belgium is about 2000 new cases per year. About 800 of them are high grade intracranial brain tumours. Brain tumours represent about 3,5%² of the totality of cancers. Every year we have about 500 new cases of glioblastoma in Belgium, the most malignant type of Brain tumours. Surgical techniques preserve a maximal quality of life, but have little impact on survival with high grade brain tumours. Radiotherapy has prolonged life expectancy for a few months. An effective systemic therapy is needed. Five year survival with glioblastoma still is a mere 2 %. In the case of less aggressive brain tumours survival might be much better, as well in numbers as in time. Brain tumours are the most common type of solid cancer with children.
- **A rare disease**, which has an impact on the diversity of registered treatments, above all in the field of medical oncology. This is due to the very complex and expensive registration procedures. There are now too many subgroups that cannot or not sufficiently be treated.
- **A kind of acquired brain deficit.** All survivors experience more or less chronic motorial, sensorial, cognitive, emotional, behavioral and communicative sequels, which prevents their reintegration of society. Brain tumours give often rise to co morbidity. Epilepsy is very common. A special attention for these chronical lesions is needed.

² Based on the statistics of the CBTRUS

3. Synopsis of the workshops

3.1 Workshop 1: Organization of Brain tumour treatment in Belgium

Chairman: Prof. Dr. Dirk Van Roost, neurosurgeon, President of the Belgian Society for Neurosurgery, Head of Department of Neurosurgery at the University of Ghent.

- The existing system in Belgium Works well compared to other European countries.
- However, it could be useful for patients and their relatives to have a better oversight about the existing system, its structure and the offered possibilities.
- The role of a well trained neuro radiologist is essential for the initial diagnosis.
- The role of a well trained neuro anatomopathologist is essential in order to ascertain the correct histological diagnosis.
- Multidisciplinary oncological consultations (MOCs) are the pivotal instrument in diagnostics and treatment as they gather experts in different fields (e.g. neurosurgeons, neurologists, neuro radiologists, neuro anatomopathologists, geneticists, radiotherapists, neuropsychologists, general practitioners, etc.
- The expertise of MOC's in a reference center should be made available for centers with basic oncological care.
- A virtual collection of the data gathered in MOC's is important.
- There is a lack of participation of general practitioners in MOC's: they have a crucial role in advising Brain tumour patients. An effort should be made to include general practitioners in the MOC's. They should be informed about the sequels of an acquired Brain deficit.
- The best classification is the existing "WHO Classification of Tumours of the Central Nervous System". It should be universally applied.
- Central registration should be done along the WHO Classification by the National Cancer Registry

3.2 Workshop 2: Diversity of Treatments

Chairman: Prof. Dr. Stefaan Van Gool, pediatric haemato oncologist, Catholic University of Leuven, and Prof. Dr. Bart Neyns, medical oncologist Free University of Brussels.

- There is a lack of transfer of knowledge in the medical field, and about the support as well.
- There is a need for a continuous supply of well organized clinical trials. Physicians should be informed about these trials.
- There is an unmet need for a broader range of treatments for patients with a recurrency.

- “Evidence based medicine” consists not only through the practice of randomized phase III clinical trials, but also through well documented case studies. This methodology is essential for the treatment of rare diseases, in casu brain tumours.
- The principle of access to treatments and solidarity is of a prime importance, and must be protected.
- Alternative treatments, such as immune therapy, deserve an extra attention and support.
- Innovative therapies have to be implemented rapidly.
- Identification and access is needed, also for patient organizations.
- In the case of a rare disease such as Brain tumours it must be possible to prescribe off label and promising therapies. A management of risk must, the early access to novel treatments, compassionate use and medical need programs must be guaranteed if safety is guaranteed. Registration in the database also has to include side-effects (immediate and long term) and the treatment protocols.
- We ask for patient involvement in the design of clinical trials. We believe that it is important for patients not only to be research subjects, but the research allies as well, and help build strategies to increase patient enrolment in clinical trials by participating in their design, including early stage trials.
- A transparent registry of clinical trials and their criteria for inclusion and exclusion should be available.
- The expertise of patient organizations should be acknowledged in each stage of treatment and support.

3.3 Workshop 3: Support of Brain Tumour Patients and their Families

Chairman: Prof. Dr. Christophe Lafosse, clinical neuropsychologist at the Catholic University of Leuven and the Rehabilitation Hospital Hof ter Schelde Antwerp; Prof. Dr. Danielle Balériaux, neuroradiologist Free University of Brussels, ULB Erasme and Vice-president of the Harvey Cushing Centrum; and Mrs. Elisabeth Ryckaert, Close Carer, Vice-president of the Werkgroep Hersentumoren vzw – Study Group Brain Tumours Belgium.

General remark: speaking about the patient we do mean the “patient system”. This means the patient and his/her partner, children and other relevant relationships.

- Brain tumour patients suffer from a kind of acquired Brain deficit. They are entitled to access to any specific institution or service.
- The support consists of various phases along their trajectory, each with their specific characteristics, which must be correctly tuned.
- It is necessary to offer Brain tumour patients and their surroundings a support of a specifically trained psychologist.

- During the acute phase there is a need for crisis management. A clinic psychologist with specific training is needed. The acute phase remains until stability is reached. A special attention ought to go to parents and children.
- During the sub acute phase there is a need for (psycho)diagnosis and neuropsychological treatment. Indicated is a clinic psychologist with a post academic or permanent formation in neuropsychology.
- There is need for a carefully neuropsychological assessment. Deficits in the motorial, sensorial, cognitive, emotional, behavioral, relational and in the field of communication should be recognized.
- Psychological assistance only can be of profit to the patient and his/her family if the support is adapted to the deficits and shortcomings of the patient.
- Information and the learning of specific skills are an essential part of the trajectory.
- A structured team is needed to reach these goals.
- An extra attention for children with Brain tumours is needed. Indeed, the rest of their lives will be influenced by the illness of their youth.
- A lifelong rehabilitation trajectory is needed for a maximal rehabilitation and re-integration.
- There are shortcomings in the following fields: specialized support, mobility, (re)employment, housing, school career, social isolation, poverty and a meaningful activity.
- Palliative or supportive care have to guarantee quality of life for patients who do not recur anymore to curative treatments. Also in this matter there is a great specificity. Patients who have lost their memory or their equilibrium for instance or patients with frequent epileptical fits need a constant support. A support adapted to the individual needs of the patient should be established. The expertise established in the care of neurodegenerative diseases could serve as a starting point.
- The patient organization has a role in matters of information and also in the social field. The expertise must be recognized. It is an essential factor in a holistic care for Brain tumour patients and their families.

4. Synopsis – Policy Recommendations

Specificity of cure and care of Brain tumour patients must be recognized. We propose the following measures in order to lessen the need of patients and their families, taking economical factors into account, and the principle of solidarity as well:

- The access to high quality treatment has to be an evidence for each Brain tumour patient. Expertise has to be bundled in a virtual expertise center. Identification of the expertise as a must for physicians and patients.

- Every center for patients with an acquired brain deficits must be at the disposition of Brain tumour patients.
- A specific entity for rare cancers should be created in order to establish criteria and quality control, not only in the medical field, but also in matters of care and social support.
- A registration of all brain tumours along the criteria of the WHO Classification of the Tumours of the Central Nervous System is necessary for epidemiological reasons and for scientific use as well.
- Therefore cooperation between data managers and neuro) anatomopathologists is indicated.
- A system of “virtual trial” may be useful as signal detection in order to make further of clinical trials for rare cancers, such as Brain tumours.
- The access to non registered therapies must be more flexible. Therefore an adaptation of the functioning of the “Special Solidarity Fund” must be executed along the lines of the report of the Federal Expertise Center.
- Quality of the Multidisciplinary Oncological Consultations must be guaranteed.
- Every Brain tumour patients and his relatives must be supported by a clinic psychologist with a post academic or permanent formation in neuropsychology.
- A neuropsychological evaluation is the starting point for a lifelong trajectory leading to rehabilitation and social re-integration, and the access to centers for people with an acquired brain deficit if needed. This problem field is often not understood and this prevents re-integration.
- There is a need for expertise and skills for professionals in the care programs, and for close carers as well. Specific training must be available.
- A lifelong rehabilitation process must be possible, where the remaining potentialities of the patient must have a central attention, and not his shortcomings. Therefore knowledge and expertise are needed for any caregiver. This is a necessary condition for re-integration in society.
- Additional measures in matters of specialized support and care, (re)employment or alternatives (such as a meaningful occupation), housing, mobility, pedagogy and cultural participation are needed.
- Palliative and supportive care must be available for all patients who cannot be treated in a curative way anymore.
- The terminal stage may be very short, but there are cases where it takes many months. Sufficient support is needed. Brain tumour patients in the terminal phase represent many similarities with neurodegenerative patients, their level of functioning and their degree of dependence.
- We recommend patient participation as a necessary aspect of the care for Brain tumour patients.

- Waiting time for support may not exceed 3 months in those cases.

Brain tumour patients are a relatively small group. Our recommendations may also be used in a transversal way with other rare cancers or rare diseases. They are also useful for other chronic brain deficits.

5. Proposal for measures resulting from the policy recommendations

1. Identification of expertise

- a. Creation of a virtual expertise center allowing a second opinion if wanted
- b. Establishment of transfer of data within the virtual center of expertise.
- c. Quality control
 - i. National regulations
 - ii. Tuning with European regulations and recommendations
 - iii. College
 - iv. 'Quality of Care Analyses'
 - v. The need for schooling
 1. Medical curriculum at all levels
 2. psycho-oncology
 3. specific module for cancers of the central nervous system and acquired brain deficits
- d. Establishment of a program of cure and care adapted to the specificities of cancer of the central nervous system, including the presence in the team of e.g. a radiologist with proven expertise in neuro radiology, a neuropsychologist, the availability of crisis support, and the access to adapted support for rehabilitation in order to optimize re-integration
- e. Optimization of the MOC structure is needed.

2. The importance of registration

- a. Creation of a registry along the WHO-classification
- b. Coupling to a virtual center of expertise

3. Access to clinical trials

- a. Through a platform where scientists and users may make contact

4. Palliative care adapted to the individual need

5. The importance of access and solidarity, two essential notions in our health systems

- a. Guaranteeing of "early access" (see also point 3)
- b. Optimization of the Special Solidarity Fund
- c. Identification of expertise (see also point 1)
- d. Early refunding of orphan drugs and promising
- e. 'Off-label use' is an important alternative
- f. Simplification of procedures should lead to a better access to support for patients and their families

6. Integration of the patient representation

- a. Patient representation is an essential aspect for cure and care of patients and their families

7. Importance of translational

8. Importance of innovative treatments

- a. Feasibility Study about hadrontherapy
- b. Access to protontherapy
- c. Improved possibilities for radiology
- d. Further development of immune therapy Verdere ontwikkeling
immuuntherapie

We hope that this proposal for measures may serve as a base for action in the future cancer plans.

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