



THE BRAIN
TUMOUR PATIENTS'
**CHARTER
OF RIGHTS**

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PURPOSE OF THIS CHARTER

To achieve the best possible health and quality of life outcomes for adults and children living with a brain tumour.

To represent an aspirational ideal against which quality standards, policies and practices are developed, monitored and delivered.

INTRODUCTION

There are a number of documents dealing with patients' rights, some of which relate to the rights listed here.

This Charter has been drafted from the point of view of the brain tumour patient and caregiver with particular consideration for the difficulties which can arise while living with a brain tumour. This Charter has been created through a multi-stakeholder, collaborative and iterative process and is a living document, subject to annual review.

It is hoped that this Charter will have worldwide relevance. We are mindful that many countries lack basic health, research and manufacturing facilities and the specialists and treatment centres with the capacity to deliver the most modern scientific evidence-based care for brain tumour patients. The Charter therefore represents an aspirational ideal which we should work towards and we hope and expect that it will prompt productive discussion and debate to help initiate positive change.

Importantly, the Charter provides a detailed framework for the achievement of policy objectives which brain tumour patient advocacy organisations can use to support their efforts. It can also be used by individual patients and caregivers to underpin the things that matter to them on their brain tumour journeys. The Charter is also meant to be a positive tool that can be used by other sectors of the international brain tumour community.

The Charter can provide everyone with an aspirational framework for improving healthcare systems and communications – goals which we hope will help reduce inequalities from country to country. The Charter is not intended to detract from or criticize the sterling work being carried out every day around the world by researchers, healthcare professionals and others.

We invite those living in developing countries – where many of the aspects of this Charter will not be easily attainable – to select those aspects of this document which are achievable in their own regions and to focus on those to help secure better outcomes for brain tumour patients.

While asserting these rights we acknowledge that no rights can exist in human society without responsibilities.

NOTES

- 1. This Brain Tumour Patients' Charter of Rights is not a guarantee of these rights, nor is it legally binding.*
- 2. This is the current version of The Brain Tumour Patients' Charter of Rights but as a living document, it is also subject to annual review, and a procedure for the Charter's further evolution will be established.*
- 3. Please see the attached appendix to this document which lists the brain tumour charities and not-for-profits, professional neuro-oncology societies and other organisations who have ratified The Brain Tumour Patients' Charter of Rights and given permission for their logos to appear on this document.*

1. ACKNOWLEDGEMENT AND RESPECT

I shall have the right to:

- a) access health care designed to reduce the burden of my brain tumour
- b) be acknowledged as a person living with a brain tumour
- c) be treated as an individual
- d) describe myself - whether I am an adult or a child living with a brain tumour - with whatever terminology I feel comfortable with
- e) be heard and acknowledged, even if the health care professional does not necessarily agree with my position or perspective
- f) be respected as a significant partner in my own care and an expert in my own needs and experience
- g) not be discriminated against in my community or my workplace or indeed anywhere at any time because I have a brain tumour
- h) maintain hope and to be supported in that hope by my medical team and others responsible for my care, no matter what the diagnosis and prognosis

2. APPROPRIATE INVESTIGATION OF SIGNS AND SYMPTOMS

I shall have the right to:

- a) information and education about brain tumours
- b) my concerns about my health to be investigated promptly by doctors with appropriate training and experience in neuro-oncology, neurology, neuro-surgery and psychosocial health.
- c) a clear explanation of medical imaging done of my brain and brain tumour and the different scanning and assessment techniques and what they can and cannot tell us

d) a clear explanation of the options for treatment of my brain tumour, e.g. surgery, radiation, chemotherapy, clinical trials etc, including the associated risks

e) my tissue/biopsy sample to be analyzed by an experienced neuro-pathologist using validated pathological/diagnostic tests (including biomarker assays) in order to provide me with a correct diagnosis

f) provide informed consent about the use of my resected tumour tissue and, if I have donated/stored brain/tumour tissue or any other bio-specimen for research or other purposes, to know if my tissue sample may be accessed for future treatment decisions and research

3. A CLEAR, COMPREHENSIVE, INTEGRATED DIAGNOSIS

I shall have the right to:

a) a timely referral to a specialist health care provider of my choice

b) receive a prompt and accurate diagnosis (based on an integrated analysis of my tumour tissue using the World Health Organization's most up-to-date classification of brain tumours, and a clinical presentation) which should be conveyed to me in a clear and compassionate manner

c) ask questions about my diagnosis and receive appropriate answers in terms I can understand

d) be accompanied to my diagnosis appointment and any subsequent appointments during the course of my treatment by a family member, close friend or other designated caregiver

e) an interpreter, if the diagnosis is delivered to me in a language in which I am not fluent

f) be proactively involved in all of the decision-making processes relating to my diagnosis and subsequent care

g) take notes in my medical appointments for the sake of clarity and as an aide memoire. Further - but only if I first get all necessary permissions to do so - to record my medical appointments.

h) request and access other opinions at any stage of my care and treatment and to be informed by a specialist if he/she believes they are unable or unwilling to perform an operation, or administer a therapy

i) be given as detailed a prognosis as possible, if requested, which includes information regarding quality of life, side effects of treatment, potential for late effects of treatment and probability of survival

j) a complete copy of all the notes taken in relation to my diagnosis by my medical providers that go into my medical records

4. APPROPRIATE SUPPORT

I shall have the right to:

a) clear, unbiased, honest, comprehensive and timely information that will help me make the difficult decisions with which I will be faced. I also have the right to challenge this information and seek clarification about anything that I do not understand

b) access decision-making tools to enable me to make the right choices for my situation

c) support from a care coordinator or brain tumour journey navigator (i.e. a specialist nurse, social worker or other trained person)

d) be offered information on legal issues that I may need to consider, for example power of attorney, guardianship of children, living wills, advance directives, etc

e) be offered appropriate information about returning to work or school and the laws in my country that govern employing or educating people with disabilities

f) participate in a brain tumour support group if one exists in my local area, attend one virtually or have the opportunity - if I wish - to establish one if it doesn't yet exist

g) be told about local, regional and international brain tumour patient advocacy organisations to whom I can turn for advice and further support

5. EXCELLENT TREATMENT AND HIGH-QUALITY FOLLOW-UP CARE

I shall have the right to:

- a) be informed about all available relevant treatment options, in my country of residence, whether (or not) the cost of delivering such treatments are reimbursed by insurance or other third parties
- b) share with my treating doctors the decision-making process in selecting the best treatment/s for me, taking into account the level of risk I am prepared to take
- c) access treatments based on need – not on my ability to pay for it
- d) receive the accepted international standard of brain tumour care, regardless of my age, race, economic background, disability, beliefs or gender
- e) receive emergency treatment to stabilise my condition at any point in my brain tumour journey
- f) continuity of care from the moment of diagnosis through treatment, recovery, disease progression, long-term survival and end of life. If I am a pediatric patient, continuity of care also includes transitioning to adult follow-up care.
- g) be treated in a healthy and safe environment where quality standards are imposed, monitored and met
- h) have my medical treatment conducted in accordance with the highest standards of ethical practice.
- i) ask for and be provided with copies of all notes and data which go into my medical record, including radiology reports, pathology reports, genetic analyses, etc., as well as digital copies or film copies of all of my scans, and to be recognised as the ‘owner’ of these records
- j) multidisciplinary care, which may include - apart from my core medical team’s help - support from other specialists such as physiotherapists, speech and language therapists, psychosocial therapists, social workers, occupational therapists and others

k) be informed if clinically-relevant delays in my treatment are expected and to be informed of alternative service providers who may be able to provide treatments sooner

l) review with my doctor the possibility of using other treatments, experimental or otherwise, in addition to (or instead of) the standard of care

m) be fully informed of all proposed treatments, their benefits and risks and, where relevant, the costs involved

n) refuse or withdraw from treatments, tests, scans and investigations without sanction or vilification

o) be told about relevant, appropriate clinical trials available in my current treatment facility and offered a place if I meet the inclusion/exclusion criteria, or be directed to the contact details for a trial taking place elsewhere for which I might be eligible

p) be fully informed of the benefits and risks involved for me and to have sufficient time, without pressure, to consider participation (or not) in a clinical trial, experimental procedures or investigational programs

q) have my trial participation, should I enroll in such a study, acknowledged and appreciated and be advised of the final outcome of the trial

r) regularly scheduled follow-up appointments and appropriate scanning and tests if I have completed treatment for my brain tumour

s) be treated by an expert health care provider for follow-up. If I am a pediatric patient, this will include being treated by an expert health care provider familiar with the late effects of treatment.

6. THE CARE RELATIONSHIP

I shall have the right to:

a) access an up-to-date contact list of neurosurgeons, radiation oncologists, neuro-oncologists, neurologists and other specialists in my area/country, as needed

b) be provided with the name and contact details of a knowledgeable staff member at

my treating facility who may be able to answer urgent questions out of hours and at times other than scheduled consultations

c) express my opinion or complain without fear of retribution if I receive unsatisfactory care at an institution. I shall also have the right to be given information on the means of expressing this opinion/complaint to management level staff and to expect my complaints to be investigated and the findings conveyed to me in a timely and comprehensive manner

d) challenge my doctor's opinion in a respectful manner and expect the same respect in return

7. SUPPORTIVE/PALLIATIVE CARE

I shall have the right to:

a) receive high quality, fully integrated, multidisciplinary early palliative care which encompasses symptom management, pain relief, psychosocial support, rehabilitation and social and spiritual support

b) receive optimal medication to relieve the symptoms and side effects of my brain tumour and its treatments such as pain, nausea, seizures, etc

8. REHABILITATION AND WELL-BEING

I shall have the right to:

a) access rehabilitation programmes (including speech and language therapy, occupational therapy, neuro-psychological therapy and physical therapy) to address cognitive, behavioural and physical deficits resulting from my brain tumour so that I can maximise my independence and recapture my ability to function as normally as possible

b) information about benefits funding (where available) to ease financial burdens

c) access wellbeing programs specific to my situation as a survivor taking into account my particular, individual needs (including family, employment, financial and psycho-social requirements)

9. MEDICAL INFORMATION AND PRIVACY

I shall have the right to:

- a) have my brain tumour properly registered in my country's (and international) cancer registration records whether my brain tumour is so-called 'benign', low grade or high grade
- b) my own personal physical space and the maintenance of dignity through all tests, investigations, treatments and procedures
- c) have conversations with medical and other professionals about my health and wellbeing which remain private between us
- d) wear appropriate clothing during treatment and care to protect my privacy and minimise embarrassment
- e) keep medical information about myself from being disclosed to other parties without my permission
- f) decide with whom, when and where to share information about my health

10. APPROPRIATE END-OF-LIFE OPTIONS AND CARE

I shall have the right to:

- a) discuss all available end-of-life care options, or be referred to other doctors who are willing to discuss them with me at any point in my brain tumour journey
- b) my primary cause of death being accurately reflected in government records as a brain tumour if such is the case
- c) the proper and appropriate quality and level of care that I decide is right for me as I approach the end of my life
- d) my dignity, and to compassion and respect from others
- e) express my wishes as to my preferred place of death, for example in hospital, at home, in a hospice, etc

f) advance care planning

g) donate any part of my body, including my brain and tumour tissue samples, to research or to refuse to do this

h) make my own end-of-life decisions and for these to be respected as far as they can be within the current laws of the country in which I am receiving treatment and/or care

THE BRAIN TUMOUR PATIENTS' CHARTER OF RIGHTS DRAFTING COMMITTEE:

Kathy Oliver, International Brain Tumour Alliance (IBTA); Gordon Oliver, International Brain Tumour Alliance (IBTA); Barrie Littlefield, (formerly of) Cure Brain Cancer (Australia); Kristina Knight, (formerly of) National Brain Tumor Society (USA); David Arons, National Brain Tumor Society (USA); Danielle Leach, National Brain Tumor Society (USA)



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APPENDIX

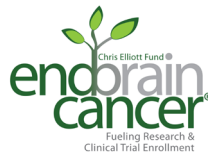
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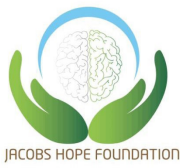
The following organisations* have ratified the Charter and support its aims:



*Organisations listed in alphabetical order

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JACOBS HOPE FOUNDATION



KORTNEY ROSE FOUNDATION



MARK HUGHES FOUNDATION



IHI A RANGI NZ Brain Tumour Trust



Bénévoles à l'hôpital pédiatrique



Volontari in Pediatria



小児脳腫瘍連絡会

PBTN

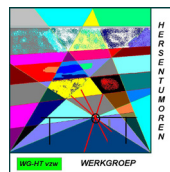
Pediatric Brain Tumor Network Japan



Philippines Brain Tumor Alliance



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*The Brain Tumour Patients'
Charter of Rights*
is a living document.
If your organisation would
like to support the Charter
please contact kathy@theibta.org



THE BRAIN TUMOUR PATIENTS' CHARTER OF RIGHTS

For further information or any questions on *The Brain Tumour Patients' Charter of Rights*, please contact Kathy Oliver, International Brain Tumour Alliance (kathy@theibta.org).

For further information on the Charter Toolkit, please contact Danielle Leach, National Brain Tumor Society (dleach@braintumor.org)

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