

The Brain Tumour Patients' Charter of Rights

TOOLKIT

The Brain Tumour Patients' Charter of Rights aims to inspire advocacy and collective action to improve the lives of people with brain and central nervous system (CNS) tumours all over the world. The Charter represents an aspirational ideal to work towards and is also meant to prompt discussion and collaboration, as well as foster awareness. This toolkit provides some ideas for the Charter's use.

- 1. Sample Press Release (attached)
- 2. Edited images for social media (attached)
- 3. Sample social media posts (below)

Use hashtags #BTPatientRights #BTSM on all posts.

You can link to the *Charter* by posting it on your own website or use the link to the International Brain Tumour Alliance's (IBTA) website at www.theibta.org

Twitter

XXXX is proud to support The Brain Tumour Patients' Charter of Rights and continues to work together with the brain tumour community to achieve these rights for every patient. #BTPatientRights #BTSM @theIBTA

XXXX proudly supports The Brain Tumour Patients' Charter of Rights so we can all work to reduce inequalities in treatment, care and support across the world. #BTPatientsRights #BTSM @thelBTA

Facebook

XXXX is proud to support The Brain Tumour Patients' Charter of Rights, an international collaborative effort to identify and ultimately foster discussion and action to improve the lives of brain tumour patients. #BTPatientRights #BTSM @theIBTA

Instagram

XXXX is excited to support The Brain Tumor Patients' Charter of Rights. We hope this will inspire patient advocacy efforts to improve the lives of brain tumour patients and their families #BTPatientRights #BTSM @theIBTA

4. Suggested activities

For Organizations (charities, not-for-profits, professional societies, etc)

- Focus group: create a focus group and initiate a discussion around the Charter.
- Landscape assessment: use the *Charter* as a tool to identify one or two key areas in which certain short-term and long-term attainable goals can be created for future work.
- **Collaborate:** build a coalition or work through an existing coalition to promote the aims of the *Charter*.
- Virtual or in-person conference session: build a session on the Charter into a virtual or in-person conference or meeting you are hosting include patients, caregivers, health care professionals, researchers, key opinion leaders and policy-makers on a panel discussing the goals of the Charter.
- Webinar: host a webinar about The Brain Tumour Patients' Charter of Rights.
- **Education:** create culturally appropriate patient education materials in your own language about *The Brain Tumour Patients' Charter of Rights* with input from patients and families.
- **Strategic plan**: integrate these rights into your organization's or group's strategic plan
- Advocate: create a patient advisory council and advocacy action plan around one or two identified rights in the *Charter* that you would like to see implemented in your country.
- Media: use the Charter as a press opportunity; create a blog; gather patient and health care professional perspectives around the rights; and share on social media.
- Policy: start a dialogue about the Charter with key opinion leaders and government departments in your country who are responsible for health care policy.
- Official awareness days/weeks/months: use these national, regional and international events to highlight *The Brain Tumour Patients' Charter of Rights* and its aims; choose one or two of the rights around which you build a themed awareness-raising project and promote those projects to your community during special awareness periods.

For Patients

- Use the *Charter* as a discussion tool with your health care providers to help improve your brain tumour journey.
- Use the *Charter* as a tool for seeking support and services.
- Encourage your health care providers to include patients in an advisory role around issues related to the *Charter*.
- Use the *Charter* as a tool for your personal advocacy.
- Write a blog/article/post on social media around a key issue identified in the *Charter.*



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Ref: This Toolkit is for V.6/2020 of The Brain Tumour Patients' Charter of Rights