2025 COMMUNITY REPORT

A summary of insights from the 2025 community feedback

braintumour
foundation
OF CANADA

A message from our CEO

At Brain Tumour Foundation of Canada, our community is at the heart of everything we do. Over the past year, we reached out to patients, survivors, caregivers, researchers, health-care professionals and supporters to gather their insights. This input not only guides the development of our next strategic plan but also ensures that our initiatives align with the needs of those who access our programs, services, and support.

Founded more than 40 years ago, our organization has always had a singular purpose: to support every person affected by a brain tumour and to strive for a future free from this disease. This mission continues to drive us today.

Every conversation, survey response and focus group has been an opportunity for us to listen and understand what matters most, where we can improve and how to strengthen the network of care and connection within our community. We extend our heartfelt thanks to everyone who participated in our survey or shared their experiences. Your honesty, insight and courage are instrumental in shaping our future direction.

As this report demonstrates, our community continues to find meaning in our programs, peer groups, educational resources and advocacy efforts.

However, you have also challenged us to reach further—to make our services more accessible, to expand our content and incorporate greater diversity in topics and perspectives, and to advocate for equitable access to treatments, clinical trials and research funding.

Your feedback reminds us why our work is so vital. Together, we raise awareness of this devastating disease that affects so many Canadians. We advocate for improved care, treatments, and support. We invest in research and provide grants to scientists who are tirelessly working to find a cure. We also offer trusted programs and information that help individuals and families navigate their diagnosis, the healthcare system and life beyond.

As we look to the future, we do so with shared optimism, guided by the voices of our community, who have spoken with honesty, strength and hope. Your voices direct our path and remind us that progress occurs when we work together. "Hope, Together" is more than just a phrase; it represents our collective commitment to increasing awareness, expanding our reach, and strengthening the support that helps people live better today while moving us closer to a cure tomorrow.

— Nicole Farrell
Chief Executive Officer
Brain Tumour Foundation of Canada

What we heard

Background and context

At Brain Tumour Foundation of Canada, our mission is to reach every person who is affected by a brain tumour through support, education, information and research. As we begin working on our next Strategic Plan (2026-2029), we want to ensure that the direction we take truly reflects the needs, experiences and hopes of the community we serve.

Our strategic planning process is built on collaboration. Whether you're a patient, survivor, caregiver, health-care professional, donor, volunteer, researcher, or advocate, your insights matter. We believe the best way to shape the future is to do it together.

To help inform our strategic priorities, we invited you to get involved with us.

1

Surveys

We distributed six surveys in English and French to gather insights on what's working, what's missing, and what matters most to you. Surveys remained anonymous and were tailored to target patients, caregivers, health-care professionals and program participants. These surveys were open for engagement between May and July.

2

Virtual focus groups

Throughout June, we connected with some of our community members to dive deeper into key topics in a small-group virtual setting. We held separate groups for patients, caregivers and health-care providers.

3

Open webform

Our open webforms were for anyone unable to participate in our surveys or focus groups.

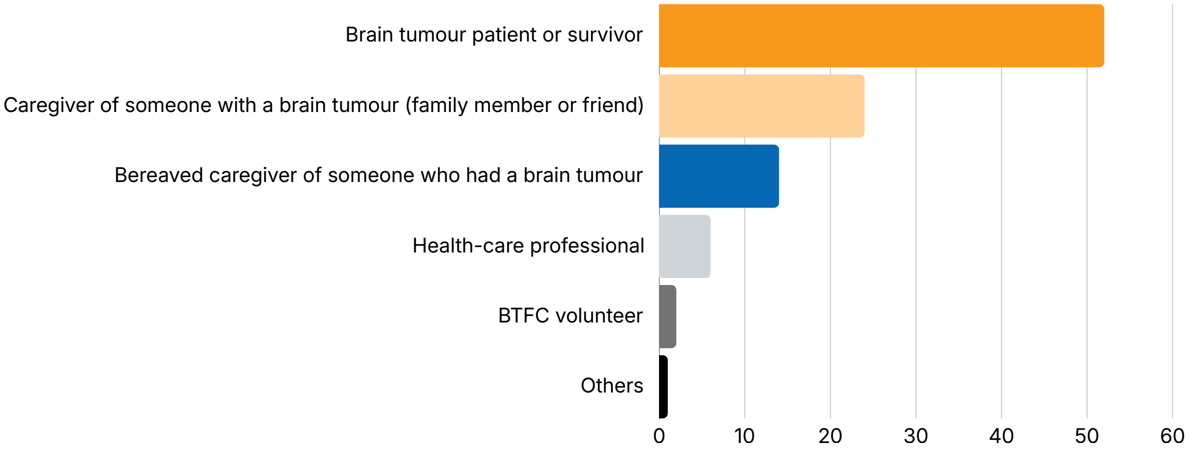
We shared these opportunities through our website and social media channels to reach as many community members as possible.

This report brings together the insights shared by survey respondents and participants, highlighting what's working well, where improvements can be made and how we can continue to grow together. The findings reflect the lived experience of patients, survivors, caregivers and health-care professionals from across Canada.

We are truly grateful to everyone who took the time to participate and share their perspectives. Your insights help guide us as we design, plan, and deliver meaningful programs for everyone impacted by a brain tumour.

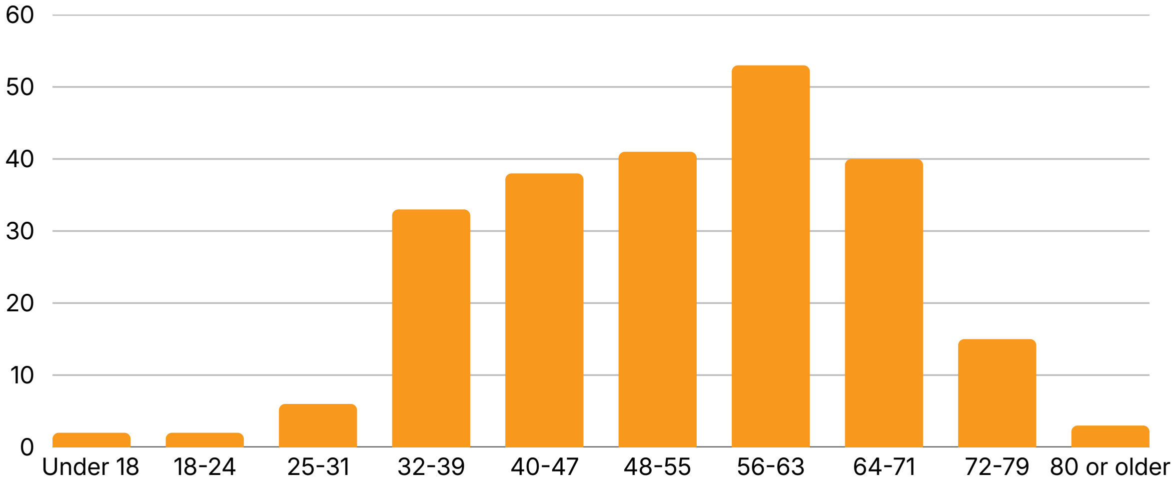
Overview of our survey respondents

Between May and July, we received over 400 responses from our community. Among survey respondents, 52% were people living with a brain tumour, including patients and survivors, while 24% were caregivers such as family members or friends supporting someone with a brain tumour. 14% were bereaved caregivers who had lost their person to a brain tumour, 6% were health-care professionals and 2% were BTFC volunteers.



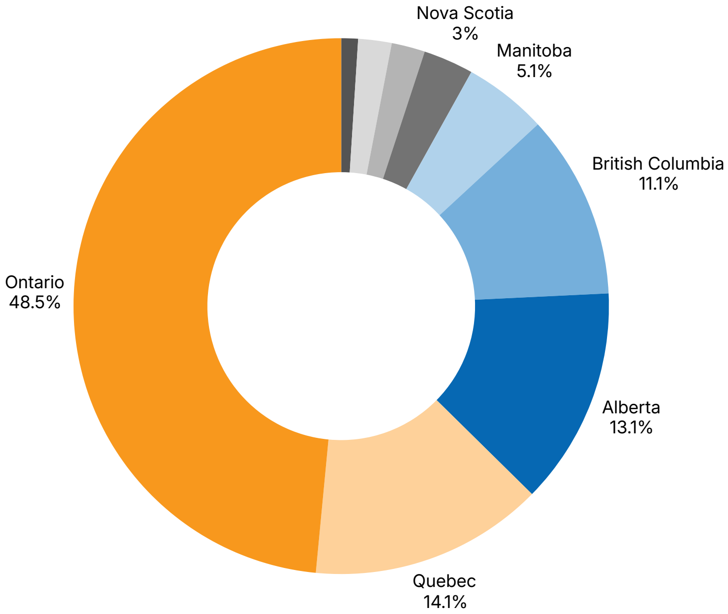
Age distribution of survey respondents

Our respondents represented a wide range of age groups within the brain tumour community. Most participants were between 40 and 71 years old, with the largest number in the 56-63 age group. We also had respondents between 25 and 39 years of age. This range reflects the diverse experiences and life stages within our community.



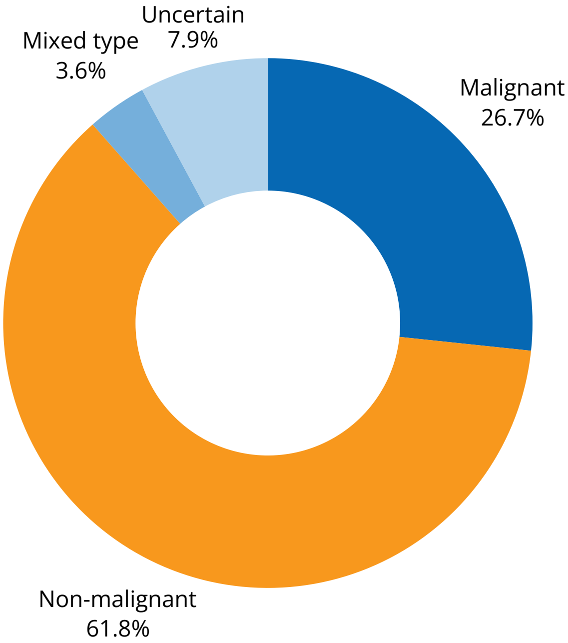
Geographic distribution

Most respondents were based in Ontario, followed by Quebec, Alberta and British Columbia. We had some participants from Manitoba, Nova Scotia, New Brunswick, Saskatchewan, and Newfoundland and Labrador. We see opportunities to strengthen outreach and engagement in regions with lower participation.



Type of tumour

Approximately 60% of participants reported being diagnosed with a non-malignant tumour, and close to 30% with a malignant tumour. A few participants reported having a mixed type of tumour or were unsure about their tumour type.



Summary of strengths and challenges

Brain Tumour Foundation of Canada offers programs, support services and resources designed to inform, support and connect people impacted by a brain tumour. Through the surveys and focus groups, participants shared their experiences with these offerings, highlighting what's valuable, identifying areas for improvement and suggesting new ways to expand and improve delivery.

The following section summarizes what we heard about our key programs, services and resources.

Barriers to accessing programs, services and resources

Some respondents shared that they did not currently need support or information or that the information they sought was missing. It was also noted that some participants found it challenging to navigate our website, which made it harder to locate or access existing resources. A few respondents also noted that certain topics have not yet been covered, limiting access to the specific information they sought. For instance, clinical trials, grief and bereavement, end-of-life care, accessing financial supports, effects of brain tumours and their treatments were suggested for new resources.

It was also noted that support services are not evenly distributed geographically. There was a desire for more in-person events to form meaningful connections.

Suggestions for improvement

Community members emphasized a growing need for peer-to-peer supports and dedicated programs for young adults. They also called for better awareness of existing programs and more opportunities for in-person connection and national events.

This underscores the importance of increasing visibility of current programs, services, and resources, expanding information on topics that matter most to the community, and ensuring that all materials are easy to find and access.

> *"We love the Brain Tumour Walks... Get everyone together, just the community behind it, was so great."*

Support groups

Support groups remain one of our most valued programs, offering space for patients, survivors and caregivers to share experiences, exchange information and receive emotional support in a safe and confidential environment. Survey participants shared valuable insights into what works well and how these groups can improve to meet community needs.

Respondents mentioned that support groups helped them connect with others who share similar experiences. Some key motivations to participate in support groups included:

- Seeking peer support and connection
- Emotional support
- Information sharing and learning
- A sense of community and companionship

What’s working well

Participants highlighted the value of meaningful peer connections and a strong sense of community built over time. Many found discussions informative and appreciated how groups were organized and facilitated. The environment was also frequently described as safe and inclusive, which encouraged honest sharing and mutual support.

What’s not working well

At the same time, respondents also identified several practical challenges. Sessions were often seen as too short or too infrequent, and seasonal breaks reduced continuity for some participants. Scheduling conflicts made it difficult for some people to attend, and new members sometimes struggled to engage because introductions took up most of the meeting time. Some people also felt that some discussions were not relevant to everyone in the group.

Suggestions for improvement

Participants shared ideas to make support groups more accessible, engaging and relevant. They suggested offering smaller or location-specific groups, as well as groups focused on specific tumour types, stages of the care journey or separate sessions for patients and caregivers. Some participants preferred occasional in-person or social events, along with improved outreach and communication to help new members engage more effectively.

Participants recommended extending the duration and frequency of meetings and potentially offering year-round options. They expressed interest in maintaining a mix of open conversations and theme-based discussions, with the topics shared in advance. They also suggested introducing breakout groups tailored to different demographics.

Respondents also emphasized the need for additional training and support for facilitators, including greater familiarity with BTFC programs, services and resources. In the coming year, we will address this by supporting ongoing training and professional development opportunities for our support group volunteers.

Some participants also highlighted a need to enhance communication, promote support groups, include professionals in some sessions, and increase the focus on the unique needs of caregivers.

> *“...But again, the support groups were the biggest one for us... I think that was really helpful...looking through that caregiver lens. I think just hearing other people's experiences was really helpful.”*

BrainWAVE

BrainWAVE is a pediatric support program for families with a child (19 years of age or under) with a brain tumour, offering free, family-friendly events and activities in select regions, including Southern Ontario, the Lower Mainland of BC, Alberta, and Quebec.

What’s working well

Families appreciated the chance to relax, have fun, and meet other families facing similar experiences. They described the events as enjoyable and valuable for building peer connections among both children and parents.

What’s not working well

Families mentioned that occasionally, scheduling and travel distance prevented them from attending, and some families also reported being unaware of events in their area. Some families also reported that certain event locations were not accessible enough.

Suggestions for improvement

Respondents asked for a wider distribution of in-person events across the country and a greater variety of accessible venues and scheduling options. They were interested in more opportunities for children and siblings to socialize, parents to connect as caregivers and practical sessions about supporting a child through treatment and recovery.

> *“The rides are all fun, but we also loved meeting some other families in the picnic pavilion time, and chatting with the BrainWAVE team."*
>
> *(On Canada's Wonderland event)*

Resources

Our resources include our brain tumour handbooks and storybook, webinars, podcasts and information on our website. These are designed to help patients and caregivers stay informed throughout their care journey and to communicate more effectively with their health-care team. Our resources ensure that everyone has access to credible information.

Some of the topics covered in our resources include information about brain tumours, treatments, clinical trials, and a variety of quality-of-life topics, and are intended for patients, caregivers, family members and health-care professionals.

What’s working well

Approximately 40% of respondents reported using a handbook in the last 5 years. They described handbooks as well written and highly useful and appreciated the option. Personal stories and young adult digital stories were appreciated for being relatable and regarded as a symbol of resilience and hope.

What’s not working well

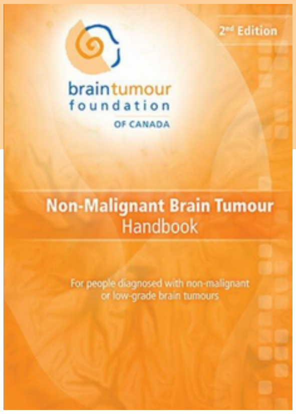
Despite consistent positive feedback on the handbooks and their quality, some respondents said they were unaware of all available resources.

Participants described the website as difficult to navigate. Despite having vast amounts of helpful information, people reported difficulty locating specific pages or topics.

Suggestions for improvement

Respondents suggested making the handbooks more readily available online, expanding on topics such as grief and bereavement, post-operative care, clinical trials and financial supports. Another suggestion was for a website redesign with improved organization and usability.

> *“I've really enjoyed the young adult digital stories...It's like my peer group, and it's really beautiful to see their stories displayed in such a way.”*



2nd Edition

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Non-Malignant Brain Tumour Handbook

For people diagnosed with non-malignant or low-grade brain tumours

6th Edition

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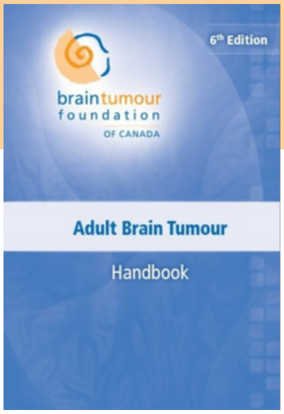
Pediatric Brain Tumour

Handbook



6th Edition

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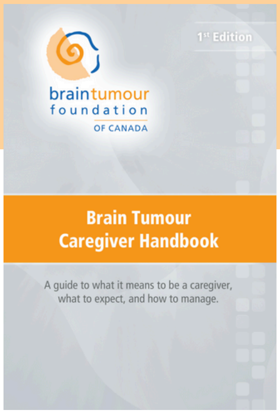
Adult Brain Tumour

Handbook



1st Edition

brain tumour foundation OF CANADA

Brain Tumour Caregiver Handbook

A guide to what it means to be a caregiver, what to expect, and how to manage.

Advocacy

Respondents highlighted barriers and challenges for us to prioritize through advocacy work. Common barriers included difficulty accessing second opinions, lack of drug coverage and financial support, and the need for improved access to new treatments and their inclusion in public drug plans. People also described challenges navigating the health-care system and expressed a desire for better awareness about our current advocacy efforts.

We noticed low levels of engagement in our Advocacy survey and will be exploring other ways to get meaningful feedback from our community.

Top advocacy priorities that were identified in our survey include-

- Timely and equitable access to effective treatment options, including emerging and innovative therapies
- Improved access to mental health and psychosocial supports
- Faster, more accurate diagnosis
- Increased funding for brain tumour research
- Financial assistance and drug coverage

Through our recent advocacy initiatives, we have contributed to projects focused on improved data collection, policy development, as well as drug and treatment access issues, including reimbursement reviews. Working alongside other organizations we also provided valuable input on the development of patient educational resources that aim to facilitate an improved understanding of the impacts of brain tumours and empower families with knowledge. Moving forward, we will continue to prioritize collaboration and working together with our community to maximize impact through advocacy.

About the organization

What are we doing well

Across all areas of work, respondents shared encouraging feedback on the organization's progress and direction. Many highlighted our CEO's leadership and appreciated the focus on transparency, relationship building, and community involvement. The intention to strengthen trust and connection has been positively received and seen as an important step forward.

Our communications were described as clear, informative and consistent. Respondents valued the organization’s active social media presence, frequent updates, and efforts to promote events and raise broader awareness of brain tumours.

The return of our in-person Brain Tumour Walks and the introduction of new fundraising opportunities have been warmly welcomed. These moments to gather, meet and honour the community were noted as meaningful highlights of the year.

When it comes to information and education, respondents recognized the value of BTFC’s handbooks, guest speakers at webinars and walks, and the website as a trusted first source of credible information. The content on non-malignant tumours was also appreciated, reflecting the organization’s efforts to ensure inclusivity.

Finally, the community acknowledged BTFC’s continued commitment to providing both emotional and practical support. Online spaces such as Facebook groups and sharing personal stories were seen as valuable sources of hope and comfort. Respondents also expressed appreciation for BTFC’s role in supporting research through funding and awareness.

> *“You are there during an extremely scary time. Often a first source of information. Invaluable!”*

What can we do better

Respondents also shared thoughtful suggestions for how BTFC can continue to grow and strengthen its impact. Many emphasized the importance of more in-person opportunities, including events, walks, and programs held in different locations across Canada, to help foster meaningful peer connections and strengthen community engagement.

Another suggestion was to improve visibility and promotion of existing programs, services and resources. Some participants noted that they were not always aware of all the available supports, suggesting that outreach could help more people benefit from what already exists.

Improving the website's accessibility and layout was also frequently mentioned. Community members preferred a more intuitive layout that could make it easier to find information and resources.

Finally, many expressed interest in more opportunities to get involved, whether through volunteering, peer mentoring or contributing to events and advocacy efforts. These ideas reflect a strong sense of commitment within the community and a shared desire to help shape the future of BTFC together.

Moving forward

The insights from this survey reflect the experiences, priorities and evolving needs of our community. They also highlight clear opportunities for growth, and as we move forward, Brain Tumour Foundation of Canada remains committed to listening and acting on the feedback we receive. Our community's voice will continue to shape our programs and services to meet the changing needs of everyone affected by a brain tumour.

Together, we will keep working toward a stronger, more inclusive community, one where every person impacted by a brain tumour feels informed, supported and connected.

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