Washington State Guide to Traumatic Brain Injury Support Groups

Washington Department of Social and Health Services

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Traumatic brain injuries (TBI) can have a significant impact on a person's physical, emotional, and cognitive functioning. Many people experiencing a TBI (and those in a caregiving or supportive role) benefit from regular connection with a TBI support group.

The Support Group Guide is a resource for those interested in creating or participating in a traumatic brain injury support group. This guide is designed to walk you through the process of creating a support group, choosing the best facilitator, managing support group sessions, and connecting with available resources to best educate, and advocate for, your support group members.

This guide was published by the <u>Traumatic Brain Injury (TBI) Strategic Partnership Advisory Council of</u> <u>Washington State.</u>



TRAUMATIC BRAIN INJURY

Strategic Partnership Advisory Council of Washington State

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Benefits of TBI support groups

Belonging and Sense of Community

Support groups bring together those with shared experiences creating a sense of belonging and community. A TBI can leave one feeling misunderstood, stigmatized or isolated. Regular connection with peers who understand TBI-related complexities provides opportunity for friendships, trusted mentorships and purpose.





Emotional Support

Support groups provide a safe and non-judgmental space to share experiences, feelings, and challenges. While every traumatic brain injury is unique, a support group can provide reassurance that you aren't alone. Others can relate, support, and listen to what you're going through. Socialization and connection can have a positive impact on mental health.

Education and Information Sharing

A valuable space for sharing information and resources, support groups are an excellent way to learn about new opportunities, research, and treatment options. Webinars and guest speakers bring new perspectives and education.

A support group is not group counseling.

It is not a replacement for mental or behavioral health counseling, medical diagnosis, treatment, or therapy. Always consult with your medical health provider to ensure your health and medical needs are being met so that you can get the most out of your support group sessions.



Types of TBI Support Groups

Virtual Support Groups

Washington state has an extensive <u>virtual support group community</u> with regular meeting opportunities including ones specifically for caregivers, veterans, youth, family and more.

Virtual Support Group Advantages:

- Connect to a group anywhere
 Find the best support group for you, regardless of geographical location.
- You control your experience
 You can control the sensory elements of the meeting, like audio volume, video use, captions, taking breaks, having nearby support, etc.
- Privacy and anonymity
 Being online can provide extra privacy and
 anonymity that isn't possible with in-person
 support groups.
- Accessibility to guest speakers and experts worldwide



Connecting to TBI experts anywhere in the world via an online platform greatly opens educational opportunities.

• Transportation is not required

Attending a support group from home makes it more accessible to those who are unable to drive or take public transportation easily. It also saves money reducing costs of gas and/or travel.

In-Person Support Groups

Some organizations offer in-person options for TBI support groups. Search online using your "community/city name + TBI support group or brain injury support group" to find available inperson support groups. If you would like an in-person support group but can't find one locally, consider starting your own using the suggestions in this manual.

Find an Online Support Group

Washington state has many active online <u>Traumatic</u> <u>Brain Injury Support Groups</u>. Established using a person-

centered approach, Washington state-led support groups focus on connection, education and engagement in life after sustaining a TBI. As part of a support group, you will learn about TBI and gain valuable coping skills, life strategies, friendships, and a sense of belonging and community.





Need help finding WIFI? Washington State Drive-in WIFI hotspots can be found at Washington State Drive-In WiFi Hotspots Location Finder.

Starting a TBI Support Group

Before starting a TBI support group, ask yourself these questions:

- **Purpose** What is the purpose and the goal of the group? Will it focus on emotional support, community building, education/information sharing (or all the above)?
- Facilitation and Safety Who will facilitate the meetings? Does your facilitator have the background and knowledge needed to support those with a TBI? Can your facilitator and location meet the needs of all participants, including physical, mental, social needs as well as medical safety (if needed).
- **Members** Will the support group cater to a specific demographic like teenagers, veterans, athletes, students, caregivers, or even the general public?
- Format and Frequency How will the support group meet? In-person or via an online format? How often will the group meet? If it's in-person, where will you meet? How long does the meeting last? As a suggestion, the meeting should last no less than 30 minutes but no longer than an hour.

Accessibility and Inclusion

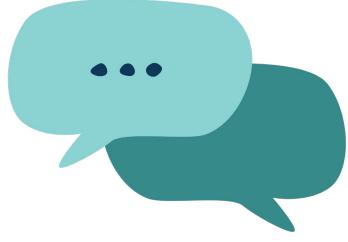
What accommodations can be established or created to enable full participation for all attendees? It's important that these needs are established as part of the group norms, rather than as a particular request for accommodation.

Establish Basic Ground Rules

Before your first meeting, establish group ground rules to keep meetings productive and respectful. Ground rules take all possible accommodations in mind - so the meeting is accessible to all. Clear and consistent support group ground rules allow members to feel confident they are in a safe and supportive environment.

Support Group Ground Rule Suggestions

- **Confidentiality** Members agree to keeping all personal information shared and conversations confidential.
- Safety Members should always feel physically and emotionally safe in a support group.
- Respect Members must respect each other's opinions, feelings, and experiences. This includes no
 interrupting, no talking over others, no judgmental comments, no unsolicited advice, and no negative
 behavior toward others.
- Attendance Members should plan to attend regularly if they are able. Regular attendance builds community, trust, and belonging.
- **Sharing** Members should feel comfortable sharing their experiences and feelings but should not dominate the conversation or monopolize the time.
- Listening Members should be actively listening, giving their full attention to others when they are speaking. Reduce or limit side conversations.



Choosing a Support Group Facilitator

Selecting the right facilitator for your support group is one of the most important steps. A group facilitator is responsible for:

TBI Lived Experience and Knowledge

TBI can be complex and often misunderstood. When choosing a facilitator, select someone who has firsthand experience with TBI. Have they experienced a TBI themselves? Have they been a caregiver or a medical provider for person(s) experiencing a TBI? A facilitator with lived TBI experience will better understand the nuances of TBI and the empathetic. Understanding person-centered practices is a good skillset for the facilitator.

Reliable Leadership

Support group members look to the facilitator as a leader. Select a facilitator with strong interpersonal skills who speaks comfortably in front of crowds and can gently guide conversation and group dynamics. As the leader serve as a role model in both reliability and behavior.

Maintaining a Safe Space

• Physical Safety

Starting with meeting accessibility, all attendees need to be able to safely access meeting space and restrooms. Emergency exits and routes should be accessible and clearly marked. Members should be aware of, and be able to access emergency exits.

• Emotional Safety

It's the facilitators responsibility to make sure confidentiality, group boundaries, and rules are respected and followed. Members feel safe to participate without emotional bullying or mistreatment.

Self-Aware, Self-Care

Facilitating a support group is more than an administrative task. It can be deeply personal and depending on the group, emotional. Choose a facilitator who is empathetic to the unique emotional support needs of those with a TBI while also having strong emotion regulation. A strong facilitator stays calm during difficult conversation and emotions. A key part of remaining calm and self-aware is proper self-care. Facilitators should have a good balance of self-care and healthy emotional habits outside of the support group.



Scan here to learn about <u>self-care</u> <u>strategies</u> and access additional resources.

Co-facilitation for Larger Support Groups

If you have a particularly large support group, consider having two people working as co-facilitators.

Managing a Support Group

Once you've established your support group and selected the right facilitator(s), these are some tips for running an established support group.

Create a Calendar

A calendar with specific dates, times, and locations of planned support groups will increase access and regular attendance.

Confidentiality is Key

Reinforce confidentiality and privacy on a regular basis.

Spread Awareness

Reach out to local hospitals, rehabilitation centers, and other organizations serving and supporting the traumatic brain injury community. Promote your group through social media.

Follow an Agenda

Creating a meeting agenda for every support group session helps attendees know what to expect and keeps members on track. Design, plan, and share the group activities ahead of time so attendees can be prepared to participate. When designing your agenda, include time to get to know each other, review the ground rules, learn something together, share opinions, and simply enjoy being together.

Agenda items can include:

- Introductions
- Icebreakers or Games
- Guest speakers
- Webinars
- Discussion topics
- Q&A
- Trauma-informed social time

Ask for Help

If you're feeling overwhelmed with the management of a support group, ask for help or leadership from other group members. Remember you are not alone. Support from other group members can increase cohesion and sense of belonging.

Make the most of free resources

- Find a free meeting location. Churches, community centers, libraries, malls, universities/schools, and rehabilitation centers are great places to look for rent-free meeting locations. If you're unable to find a free community meeting space, consider hosting a virtual support group.
- Donated refreshments. If you'd like refreshments for attendees, consider a potluck-style support group in which participants bring what they can. You can also reach out to local businesses for donations. Fundraisers can also help to offset refreshment costs.
- FREE educational opportunities. There are many FREE TBIrelated materials, webinars, guest speakers, and events in Washington State to support knowledge and information sharing for support group participants.

Seek Feedback

Set up a schedule or system to regularly receive feedback and input. Ask group members how they feel, what they like or dislike, and for their ideas or suggestions for future meetings. Regular feedback opportunities enable members to be heard and adjustments to be made that meet the needs of the group.



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Attending TBI Support Groups

Participating in your first TBI support group can be intimidating. Here are some tips for your support group experience:

Introduce yourself

• Share a little about yourself and if you're comfortable, share a little bit about your experience with TBI. This helps connect you to others and you may find others with similar experiences or feelings.

Be a good listener

 Be prepared and willing to listen to others and their TBI experiences. Hearing others experience similar things can make you feel less alone and less misunderstood. Learn from experiences to get insights and ideas for coping skills and strategies.

Be open-minded

• You never know who you'll meet or what you'll learn in a support group setting. Be open to learn from others. Remember that no two TBI are the same, so you may learn about different perspectives or coping strategies.

Respect others

 Not everyone will have the same feelings and opinions that you do. Avoid making judgments, assumptions or giving unsolicited opinions.

Ask questions

• If something is confusing or you'd like to learn more, ask questions! Support groups are a safe place to learn. Not everyone will come with the same background. Asking questions gives everyone a chance to learn and provides opportunity for shared experiences.

Listen to your body

 Support groups can feel overwhelming, especially at the beginning. Take care of yourself during and after the meeting with breaks and asking for support if needed.

Not every support group is created equal. If you try one and it's not a good fit, keep trying. Due to the complexities of a TBI, you may find that other types of support groups also have value, depending on your needs:

- Behavioral and mental health
- Trauma-informed
- Guided mediation
- Healing with music and art
- Partners and spouses
- Goal development and strategies
- Alcohol and drug dependency

- Anxiety or panic
- Caregiver
- Veteran
- Relationships
- Grief and loss
- Depression





TBI Learning Resources for Support Groups

The <u>Traumatic Brain Injury (TBI) Strategic Partnership Advisory Council of Washington State</u> has put together a collection of learning support resources that can supplement your support group agendas and help those experiencing a TBI:

TBI Resources and Workbook filled with information, resources, journal prompts, and more. Free download available for personal or client use. Share it at your Support Group today!

<u>Capable Caregiver Manual</u> covering TBI brain function and injury basics, trauma-informed and person-centered tools, supportive communication, and more. Includes resources for caregiver self-care. Available in 13 languages with additional languages available upon request.

<u>TBI Skill Builder</u> is a 5 hour course designed for anyone working with TBI. It can be completed at your own pace.



University of Washington TBI BH ECHO – Connecting with Experts (uw.edu)

Connects service providers and professionals with virtual trainings to support patients, clients, caregivers, and families. Trauma-informed interactive learning with experts in TBI case consultation and care coordination. Monthly online clinic held 1st and 3rd Fridays 12-1:30 pm. Presentation materials and recordings available.

WA211.org is a free confidential community service and your one-stop connection to accessing the social and health services you need.

Call 2-1-1 or text 211WAOD to 898211 to connect with a specialist who actively listens to your story and can connect you to 32,000+ resources statewide. Specially trained in TBI-related needs they can assist with housing and shelter needs, utility assistance, food, transportation, health and medical care, childcare assistance, more.



<u>SafeKids Washington</u> is a series of training modules and learning resources for parents, caregivers, and youth. Connect with local coalitions for safety and prevention awareness efforts, such as helmet and lifejacket distribution, traffic and pedestrian safety, and more.

<u>Return to School</u> is designed to support parents, caregivers, school faculty, administrators, sports coaches, and athletics staff with awareness and tools to prevent injury, identify TBI, access resources, and provide support around TBI at school and during school activities.



Scan here to access the TBI Events Portal, where you can find information about future events, recorded webinars, and other resources.