



American Brain Tumor Association

## REACHING OUT FOR SUPPORT

We live in a world of choices. There are many ways to reach out for support. However, not all ways are appropriate for everyone. We offer some information to consider in helping you decide which form of support might be the right one for you.

### SUPPORT GROUPS

There are face-to-face brain tumor support groups throughout the country. Most of these groups are open to both patients and family members. If it is a large group, patients and family members might meet separately. A typical group is one that is open and ongoing. This means that new members join the group, and others leave, as their needs change. Though there can be much stability in these types of groups, it is important to keep in mind that as the composition of the group changes, so will the personality of the group.

In contrast, there are other groups that are time-limited, closed groups. This means they operate for a fixed period of time, say 6-8 weeks with the same individuals. Once the group starts, it is closed to new members until the end of that time period. After that time period, a new group forms with new individuals.

All groups, whether open or closed, ongoing or time-limited, may meet weekly, monthly or quarterly, depending on the needs and desires of the group members and the availability of the facilitator(s). Some support groups are professionally facilitated and some are not. A professionally facilitated group is one in which a professional, such as a social worker and/or nurse, provides guidance and direction to the group. He or she also monitors the interaction among the members to make sure that everyone's needs are being addressed. Those that are not professionally facilitated more closely resemble self-help groups.

Support groups vary in their formats. Some are strictly supportive, while others might be strictly educational; still others might draw from elements of both.

The major advantage of face-to-face support groups is the warmth and closeness that can develop when people interact on a personal level. In addition, since face-to-face groups draw their participants from a specific geographic location, there is a familiarity that comes from shared community experiences that can strengthen bonds among participants.

The drawbacks of face-to-face groups include the fact that you are limited by whether or not there is a group in your area. Moreover, even if there is a group accessible to you, there may be difficulties in physically getting to where the group meets, and making time in your schedule to attend the group.

To find a support group in your area, call the ABTA Social Work office at 800-886-2282, or email us at [socialwork@abta.org](mailto:socialwork@abta.org).

## ONLINE SUPPORT RESOURCES

Online support resources can provide an important option for those who do not have access to regularly scheduled face-to-face support groups, or for those who prefer e-communication. They offer opportunities to communicate with a large number of individuals who are in similar circumstances. There are many different kinds of online support groups.

Chat rooms are generally real-time discussion forums, similar to a phone call among a large number of individuals, except that the conversation is written and not heard. They may be moderated or unmoderated. Those that are moderated have someone screening the material so that inappropriate text is not posted.

E-mail discussion groups, sometimes called listservs, and bulletin boards are forums where messages can be posted and read by individual subscribers. They are not real-time in that individual subscribers can read the posts at different times according to their own schedules. This form of communication is more like reading a letter than talking on the phone. The letter can be read, thought about and responded to at the reader's convenience. Most listservs require that you subscribe or register prior to sending a message. They may also be moderated, or not. In moderated groups, someone is responsible for screening the messages to make sure they are not offensive, pertain to the subject, and conform to the purpose of the forum. A moderated forum lends a degree of control and predictability over the content of the messages that are posted.

Another factor to consider is the privacy policy of an online forum. A privacy policy is a statement telling users whether or not personal information about them is being collected as they use the forum, how that information is stored, and whether it is passed along to people outside the forum.

The advantages of online forums are that they are not limited by distance and time. They also allow you to communicate with a potentially large number of individuals, far beyond those in your immediate geographic vicinity. In addition, you don't have to be available at a certain time each week or each month. You can go online to "check-in" with the forum, read, and send e-mails at your leisure.

Drawbacks include the privacy concerns mentioned above, as well as the potential anonymity of the participants. Though your communication can appear very personal, as if you are communicating with just one person or a small group, you are actually communicating with everyone who is a member of that forum. Every group may have "lurkers". This can be a large number of people who do not regularly post on the list and remain anonymous and "invisible" to you. You should also bear in mind that Internet communication is inherently not private,

despite the best efforts of the sponsors to adhere to their stated privacy policy. Therefore, only share what you are totally comfortable in sharing.

A description of online support forums we've found are listed at the ABTA web site:  
<http://www.abta.org/index.cfm?contentid=225>.

## ABTA CONNECTIONS "PEN PAL" PROGRAM

This is a program that connects individuals, who are dealing with a similar type of brain tumor, or who share an interest in a certain type of treatment. It is open to both patients and family members. The emphasis is on shared experiences to promote information exchange and mutual support. This type of connection is one-on-one though, not face-to-face. Participants in this program can communicate through letters, telephone calls or email, however they feel most comfortable.

Its advantages include a more personal way of sharing that is not limited by geographic proximity, and a connection based on shared interests. This is not always the case, as for example, in support groups, where there can be a variety of individuals, with different types of brain tumors.

Their drawbacks include the fact that it is limited to one or two persons and therefore does not provide the variety and scope of input that face-to-face groups and Internet-based forums can provide. In addition, because it is one-on-one, you don't have the luxury of limited participation, as can sometimes be possible in both face-to-face groups and Internet-based forums. You can find out more information about our pen pal programs at [www.abta.org/index.cfm?contentid=157](http://www.abta.org/index.cfm?contentid=157).

## INDIVIDUAL/FAMILY COUNSELING

Professional counseling can be of benefit when dealing with more complex issues or when you feel that informal support is not adequate to your needs. Clinical social workers, clinical psychologists, marriage and family therapists and clinical professional counselors can offer one-on-one and/or family counseling when more formal assistance is needed. For help in locating a professional counselor or therapist, you can contact the organizations listed below. Feel free to ask any professional you are considering about their expertise and experience working with individuals and families who are coping with the stresses of a medical illness.

## AMERICAN PSYCHOLOGICAL ASSOCIATION 800-964-2000

<http://locator.apahelpcenter.org/>

A psychologist can help you cope with many of life's problems. To locate a psychologist in your area use the APA's online locator service, enter your zip code or a city and state and click "Search". You can also obtain a referral to a psychologist in your area by calling their toll-free number.

AMERICAN PSYCHOSOCIAL ONCOLOGY SOCIETY  
REFERRAL LINE

866-276-7443

[www.apos-society.org/survivors/helpline/helpline.aspx](http://www.apos-society.org/survivors/helpline/helpline.aspx)

APOS has a toll-free Helpline through which cancer patients and caregivers may obtain referrals for local counseling services throughout the United States. This program aims to connect cancer patients and their caregivers to psychiatrists, psychologists, nurses, social workers and counselors skilled in the management of cancer-related distress.

NATIONAL ASSOCIATION OF SOCIAL WORKERS

202-408-8600

[www.socialworkers.org/resources](http://www.socialworkers.org/resources)

Click “Find a Clinical Social Worker.” The NASW Register of Clinical Social Workers provides a listing of clinical social workers that have met national standards for education and experience established by the NASW Competence Certification Commission.

NATIONAL BOARD OF CERTIFIED COUNSELORS

336-547-0607

[www.nbcc.org](http://www.nbcc.org)

Click “Find a Counselor.” CounselorFind, a special area of NBCC.org, is designed to help you find a professional counselor. All of the counselors in our directory hold the National Certified Counselor (NCC) credential. Individuals who hold the NCC have met high standards of education and experience and have passed a national examination. They also adhere to NBCC's Code of Ethics within their professional practice.

AMERICAN ASSOCIATION FOR MARRIAGE AND FAMILY  
THERAPY

703-838-9808

[www.aamft.org](http://www.aamft.org)

Click “TherapistLocator.net.” Only those professionals who have met the requirements for AAMFT Clinical Membership will be listed on this locator service.

NEUROPSYCHOLOGIST

A Neuropsychologist is a mental health professional with expertise in assessing and treating problems of psychological functions and behavior, as they relate to the brain and central nervous system.

A neuropsychological evaluation involves a variety of tests to assess one’s ability to remember, pay attention, use language, problem-solve and conceptualize. It can also assess perceptual and motor abilities, emotional state, behavior and personality. A complete assessment can take 6-8 hours.

Neuropsychological treatments include teaching ways to help individuals improve their impaired functions by learning strategies to compensate for lost or weakened abilities, despite limitations.

When seeking a neuropsychologist, one factor to consider is whether or not the psychologist is board certified. Board certification refers to the certificate received once post-training examinations have been successfully passed. This is a mark of high distinction in the profession. Your neurologist or neurosurgeon can help you find a board certified neuropsychologist. You can also contact the following professional organizations.

AMERICAN ACADEMY OF CLINICAL NEUROPSYCHOLOGY  
734-936-8269

[www.theaacn.org](http://www.theaacn.org)

To locate a board-certified neuropsychologist in your area, click “Member Directory.” All Academy Members are Board-Certified in Clinical Neuropsychology by the American Board of Professional Psychology.

AMERICAN BOARD OF PEDIATRIC NEUROPSYCHOLOGY  
574-232-4453

[www.abpdn.org](http://www.abpdn.org)

To locate a board-certified pediatric neuropsychologist in your area, click your state.

## TELEPHONE SUPPORT PROGRAMS

The organizations below offer one-on-one telephone support with other patients who are dealing with the same type of cancer and treatment concerns. The advantages of these types of programs are that the matches are generally made quickly and the contact is via the telephone for real-time support. The disadvantage is that matches are limited by the volunteers that each organization has at the time of your request.

ANDERSON NETWORK  
800-345-6324

[www.mdanderson.org/departments/andersonnet/](http://www.mdanderson.org/departments/andersonnet/)

The Anderson Network is a unique cancer support group of more than 1,300 current and former patients who know just what you're going through, and can offer the right patient-to-patient advice and encouragement when you need it most. They offer support to both cancer patients and caregivers. They will try to match you with a member who has had the same diagnosis and treatment--someone who understands your particular anxieties, questions and fears.

## CANCER HOPE NETWORK

877-467-3638 (877-HOPENET)

[www.cancerhopenetwork.org](http://www.cancerhopenetwork.org)

Cancer Hope Network offers free one-on-one emotional support. Support is provided via telephone by trained volunteers. Patients are matched up based on cancer type, treatment, side effects, stage, age and gender. They are only able to match adult patients with malignant brain tumors at this time. They will match up caregivers as well.

## R. A. BLOCH CANCER FOUNDATION - CANCER HOTLINE

800-433-0464

[www.blochcancer.org](http://www.blochcancer.org)

The Cancer Hot Line consists of a group of individuals who have had cancer who are available to talk with newly diagnosed cancer patients, promptly upon diagnosis.

## ULMAN CANCER FUND FOR YOUNG ADULTS - SURVIVORS AND LOVED ONES' NETWORK

888-393-FUND

[www.ulmanfund.org](http://www.ulmanfund.org)

The Survivors and Loved Ones' Network matches up survivors, parents and other young adults affected by cancer with another for peer support, mentoring and information exchange. They have recently partnered with Imerman Angels to enhance this service. There is a short survey to complete at their website after which you will be contacted by a network coordinator from one of the organizations.

## ABTA SOCIAL WORK DEPARTMENT

Our social workers are available by email or phone to help you sort through some of these considerations, so you can decide which of these ways of reaching out is best for you. Please understand there is no right or wrong to any of these options. What might be a very good support resource for one person simply isn't right for another.

We hope this summary has provided some useful information to help you make the right decision for you. Please feel free to call us at 800-886-2282 and ask for our Social Work department if you have any questions or would like additional suggestions.

The American Brain Tumor Association does not endorse any of the organizations listed, nor guarantee that individuals will qualify for the services they provide. Please contact each organization for their specific guidelines.

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