



American Brain Tumor Association

RESOURCES FOR ADOLESCENTS AND YOUNG ADULTS (AYA)

Being an Adolescent or Young Adult (AYA) is an exciting time in your life. You are filled with energy, enthusiasm and new ideas as you embrace your new found independence. During this time, you may also experience many life changes such as graduating high school, entering college or a new career, getting married or starting a family.

Oftentimes, the normal life changes associated with this life stage can become more challenging when an illness is involved. The diagnosis and treatment of a brain tumor can interfere with your normal activities and as a result, you may feel isolated and disconnected from your peers as they may not be able to relate to your needs and concerns. The isolation can also be experienced in the health care system as your needs vary from those of the pediatric and older adult populations.

To help address your specific needs as an adolescent or young adult, we have created a new Social Work resource to help connect you to the AYA Community. This community is vast and growing rapidly. More importantly, the AYA community is aware of your specific needs and concerns. Topics on this resource include: advocacy, camps/retreats, financial assistance/scholarships, fertility, intimacy and sexuality, networking sites and support services. We hope this information will provide you with specific information and also help to connect you to other adolescents and young adults.

ADVOCACY

I'M TOO YOUNG FOR THIS! (i[2]y)

877-735-4673

www.imtooyoungforthis.org

I'm Too Young For This Cancer Foundation, i[2]y, is a survivor-led advocacy, support and research organization working exclusively on behalf of survivors and care providers under the age of 40. i[2]y offers a collection of AYA resources which includes information on scholarships, retreats and online forums. i[2]y also offers a newsletter, radio show and live broadcasts. With over 16 chapters worldwide, their mission is to end isolation and improve quality of life through social media, music, the arts and grassroots community development.

SEVENTY K: ADOLESCENT AND YOUNG ADULT CANCER ADVOCACY

www.seventyk.org

Seventy K is a campaign which strives to raise awareness for the rights and needs of the AYA population in the medical community. Seventy K maintains a bill of rights to be established as a standard of care for the AYA population.

VITAL OPTIONS INTERNATIONAL

www.vitaloptions.org

Vital Options International is a non-profit communication, support and advocacy organization. Vital Options originally began as the first psychosocial and advocacy organization for young adults with cancer. Several years ago, the National Young Adult Awareness Week was launched and now takes place annually from April 6-April 12. During the month of April, Vital Options' talk radio show (called the Group Room) broadcasts young adult programming all month. Vital Options also provides a number of resources and information for young adults on their website.

CAMPS/RETREATS

CAMP MAK-A-DREAM

406-549-5987

www.campdream.org

Camp Mak-A Dream offers cost free camps to children, teens, young adults and their siblings. Camp activities include: hiking, fishing, arts, crafts, ropes courses, carnival and pool parties to name a few. Camps for teens and young adults also offer group discussions, guest speakers and workshops.

CROSSING THE FINISH LINE

267-708-0510

www.crossingthefinishline.org

Crossing the Finish Line offers a week long expenses paid retreat for young adult cancer patients and their families. Patients must be diagnosed with cancer, be between the ages of 24-50 and reside in Pennsylvania, New Jersey or Delaware to qualify.

DREAM STREET FOUNDATION

DREAM STREET AT CANYON RANCH

323-951-1227

www.dreamstreetfoundation.org

The Dream Street at Canyon Ranch program is specifically for young adults between the ages of 18-24. This program gives young adults the opportunity to escape their complex lives and medical problems. Topics of focus include: transitional issues, nutrition, fitness, relationships and self-image to name a few.

EAGLE MOUNT BOZEMAN

406-586-1781

www.eaglemount.org

Two programs are offered at Eagle Mount Bozeman. The first program, Big Sky Adventure Camp, is for ages 10-18 and is free of charge for cancer patients and parents. The second program, Young Adult Retreat, is for ages 16-23 and for patients who are in remission. Both programs offer a wide array of outdoor recreational activities.

FIRST DESCENTS

970-845-8400

www.firstdescents.org

First Descents offers adventure programs for the young adult cancer population (ages 18-39) which utilize the beauty and healing properties of the outdoors. Programs include kayaking, climbing and assorted outdoor adventures.

MINNIE PEARL FOUNDATION YOUNG ADULT CANCER SURVIVOR RETREAT

877-467-1936

www.minniepearl.org

The Minnie Pearl Foundation offers an annual retreat at no charge for young adult cancer survivors, diagnosed as adults (after age 18) and are currently between the ages 20-35. The retreat offers fun, activities, sharing of experiences and learning from an expert panel which includes an oncologist, fertility specialist, oncology social worker and a licensed dietician. Call the Foundation for more information about the retreat.

NEXT STEP

617-864-2921

www.nextstepnet.org

Next Step partners with other organizations to provide life changing retreats and workshops all across the United States for young adult survivors of childhood cancer, young adults diagnosed with cancer and young couples dealing with cancer.

OKIZU FOUNDATION TEENS N' TWENTIES (TNT) PROGRAM

415-382-9083

www.okizu.org

The TNT program offers weekend recreation and support programs to patients and siblings between the ages of 18-25.

PLANET CANCER
YOUNG ADULT RE-ORIENTATION
512-452-9010

www.planetcancer.org

Weekend retreats are available for young adults between the ages of 18-40 and also for young couples. Guest speakers will highlight various topics specific to the needs of the AYA population. Participants will also have time for networking and recreational activities. Retreats are free of charge to participants.

YOUNG ADULT CANCER-CANADA
RETREAT YOURSELF
877-571-7325

www.youngadultcancer.ca/

Retreat Yourself is an annual weekend retreat for young adult cancer survivors and their caregivers who reside in Canada. Topics discussed during the retreat include fertility, friends and finances. A number of recreational activities are also offered. This weekend retreat is free of charge to young adult cancer survivors and their caregivers.

FINANCIAL ASSISTANCE/SCHOLARSHIPS

AMERICAN BRAIN TUMOR ASSOCIATION (ABTA)
800-886-2282

www.abta.org

The American Brain Tumor Association offers two comprehensive resource listings entitled, *Financial Assistance Resources* and *Scholarships and Education Financial Aid Resources* which provide information that is specific to the AYA population.

FERTILITY, INTIMACY AND SEXUALITY

ADOPTION AFTER CANCER

<http://groups.yahoo.com/group/adoption-after-cancer/>

This listerv is for those who wish to share information, advice support and stories to those who choose to adopt after cancer.

AMERICAN ASSOCIATION OF SEXUALITY EDUCATORS,
COUNSELORS AND THERAPISTS (AASECT)
804-752-0026

www.aasect.org

AASECT is a non-profit interdisciplinary professional organization. To locate a professional, click the "Locate a Professional" tab and enter your country and state information.

AMERICAN CANCER SOCIETY (ACS)

800-ACS-2345

www.cancer.org

ACS is a nation-wide, community-based voluntary health organization. ACS provides a wide variety of information on sexuality and fertility which includes fact sheets, frequently asked questions and publications.

AMERICAN FERTILITY ASSOCIATION (AFA)

888-917-3777

www.theafa.org

The AFA is a non-profit organization which provides information on infertility treatments, reproductive and sexual health and family building options. Messageboards, online chats, magazines, print newsletters and e-newsletters are all available. The AFA also provides a professional network to locate physicians and therapists.

CANCERBACKUP

0808-800-1234 (UK)

www.cancerbackup.org.uk

CancerBackup is a national cancer information service in the United Kingdom which provides information on sexuality, infertility, relationships and a number of other related topics.

CANCER.NET

888-651-3038

www.cancer.net

Cancer.net provides oncologist-approved cancer information from the American Society of Clinical Oncology. Fertility and pregnancy information for teens and young adults is available at the website.

FERTILE HOPE

888-994-HOPE

www.fertilehope.org

Fertile Hope is a national, non-profit that is dedicated to providing reproductive information, support and hope. Fertile Hope provides information on how to locate a physician or fertility professional, a toll-free information hotline and a number of educational publications including the *Cancer and Fertility Guide for Young Adults*. Message boards and survivor stories are also available for networking and communication.

PREGNANT WITH CANCER NETWORK
800-743-4471

www.pregnantwithcancer.org

Pregnant with Cancer Network is a national non-profit organization which connects women who are pregnant with cancer with women who have been pregnant with the same type of cancer. The website includes articles, survivor stories and a book corner.

MISCELLANEOUS

LOOK GOOD, FEEL BETTER FOR TEENS

www.lookgoodfeelbetter.org/audience/teens/program.htm

This program is designed to help teens deal with the appearance, health and social side effects of cancer treatment. It is a hospital- based public service program that is offered in 16 cities nationwide. An online component for teens called, 2BMe, was designed to reach teens everywhere. 2BMe provides information on skin care, hair care, fitness, friends and fashion.

PATIENT ADVOCATE FOUNDATION
800-532-5274

www.patientadvocate.org

The Patient Advocate Foundation is a national, non-profit organization which offers a variety of resources, publications and programs. An informative publication for the caregivers of young adults entitled, "Too Young to be Ill" is available at the website.

NETWORKING SITES

ABTA GROUP ON FACEBOOK
AMERICAN BRAIN TUMOR ASSOCIATION (ABTA)
800-886-2282

<http://www.causes.com/braintumor>

Join the ABTA group to network and socialize with other brain tumor survivors and individuals who share the same cause. View photos, videos and upcoming ABTA events.

GROUP LOOP
202-659-9709

www.grouploop.org

Group Loop is an online community for support, education, and hope for teens with cancer and their parents. Networking options include online support groups, discussion boards and a "friend's database."

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NATIONAL BRAIN TUMOR SOCIETY (NBTS)

800-934-2873

www.braintumor.org

NBTS is a non-profit organization which serves those affected by brain tumors. NBTS offers message boards and blogs for young adult brain tumor survivors.

PLANET CANCER

512-452-9010

www.planetcancer.org

Planet Cancer is an online community of young adults with cancer. At this website, there are a number of opportunities for social networking via blogs and chat forums. Planet Cancer's website also provides a wide variety of information for the specific needs of young adults.

PREPARE TO LIVE (P2L)

www.preparetolive.org

Prepare to Live is a unique non-profit organization which is founded and managed by cancer survivors. P2L is dedicated to using the power of web and film to build the young adult cancer community. Through P2L, young adults can share their story in writing or through film. An ongoing short film festival is available at the website for participants to submit their own short film. Participants also can share experiences with other young adults by connecting through the Buddy Search or share artwork through a collaborative art project, the White Square Project.

STARBRIGHT WORLD

www.starbrightworld.org

Starbright World is an online support network for teens with chronic and life threatening illnesses and their siblings. Teens can connect via bulletin boards, chat rooms and blogs.

TEENS LIVING WITH CANCER

www.teenslivingwithcancer.org

Teens Living with Cancer provides facts about cancer and tips for coping and healthy living. Teens are also able to connect with one another via discussion boards and teen connection stories.

YOUNG ADULT CANCER-CANADA

877-571-7325

www.youngadultcancer.ca/

Young Adult Cancer Canada focuses on inspiring, informing and supporting young adults between the ages of 15-39. Blogs, forums and young adult survivor stories are available at the website.

YOUNG CANCER SPOUSES

www.youngcancerspouses.org

The mission of Young Cancer Spouses is to bring together young spouses of adults with cancer to share information, support and experiences. This website offers tips for caregivers, opportunities to share stories and message boards for networking.

SUPPORT SERVICES

AMERICAN BRAIN TUMOR ASSOCIATION (ABTA)

800-886-2282

www.abta.org

The American Brain Tumor Association offers a Pen-Pal program called Connections. In this program, brain tumor survivors are matched up with one another to share experiences and support one another. Pen-pals communicate via email, telephone or letter. For participants under the age of 18, a signature is required by a parent or legal guardian.

BEYOND THE CURE

800-532-6459

www.beyondthecure.org

Beyond the Cure is a program of the National Children's Cancer Society and was created for the survivors of childhood cancer. This website provides a variety of information which covers topics to include: relationships, employments and emotional issues to name a few. Beyond the Cure also offers a free publication entitled, *The Mountain You Have Climbed: A Young Adults Guide to Childhood Cancer Survivorship*.

CANCERCARE

800-813-4673

www.cancercare.org

CancerCare is a national, non-profit organization that provides free, professional support services to anyone affected by cancer. Specialized programs and publications for young adults are available.

CANTEEN

www.canteen.org.au/

Canteen is a national support organization for young people (ages 12-24) living with cancer in Australia. Canteen offers education programs, support programs and recreational activities.

GROUP LOOP

202-659-9709

www.grouploop.org

Group Loop is an online community for support, education, and hope for teens with cancer and their parents. Networking options include online support groups, discussion boards and a “friend’s database.”

IMERMAN ANGELS

312-274-5529

www.imermanangels.org

Imerman Angels is a national non-profit organization that connects cancer survivors or caregivers with one another as a way to provide support, encouragement and friendship.

ULMAN CANCER FUND FOR YOUNG ADULTS

www.ulmanfund.org

The Ulman Cancer Fund for Young Adults provides comprehensive support resources for young adults with cancer and their families. Support resources available include support groups, networking events and a survivor/loved ones network. Educational publications scholarships for young adults are also available.

This information is not intended as a substitute for professional medical advice and does not provide advice on treatments or conditions for individual patients. All health and treatment decisions must be made in consultation with your physician (s), utilizing your specific medical information. The American Brain Tumor Association does not endorse any of the organizations listed or guarantee that individuals will qualify for the services they provide. Please contact each organization for their specific guidelines.

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