Evidence from Experience - The Untapped Resource
June Alexander

The Value of Experience

“In 2009 I attended my first ANZAED conference in Brisbane. I felt a bit of a fraud, like I did not belong. I had no professional skills in eating disorder care. I had no letters to add after my name. I did not even have an employer. I was on a disability pension. But I did have experience, more than four decades of it, of living with eating disorders.

Listening to the researchers speak about their work was akin to switching on a bright light in a dark room. The dark room represented the 44 years I lived as a prisoner of my ED; the power of the illness that had held me inwardly captive was being turned outwardly with equal magnetic force. I wanted to join others in telling the world about how survivor and family experience can inform best practices and empirically-based treatments.” June Alexander

Today, a groundswell of parent/carer and survivor initiatives is helping to bridge the gap between research and recovery.

Best practice and good treatment outcomes depend on our ability to listen to all stakeholders and strengthen our partnerships with each other:

Patients, Families, Clinicians and Researchers

The Worldwide Charter for Action

www.aedweb.org/source/Charter

The World Wide Charter for Action on Eating Disorders was founded by the Academy for Eating Disorders with input from patients and families. It is a global paragon of patient, family, clinician and researcher partnership.

The World Charter identifies six basic rights of patients and carers:
1. Right to communication and partnership with health professionals
2. Right to comprehensive assessment and treatment planning
3. Right to accessible, high quality, fully funded, specialized care
4. Right to respectful, fully informed, age appropriate safe levels of care
5. Right of carers to be informed, valued, and respected as a treatment team resource
6. Right of carers to accessible, appropriate support and education resources

Many individuals and organizations across the world have endorsed the Charter, and advocacy groups continue to seek its endorsement.

Action: The Academy for Eating Disorders Patient Carer Task Force is promoting global acceptance of the World Wide Charter as Best Practice for treatment and prevention of eating disorders by developing a social networking strategy.

Place the World Wide Charter in a prominent place on your wall!

MentorCONNECT

www.mentorconnect-ed.org

Shannon Cutts, Founder: A survivor, Shannon oversees the first global mentoring community that serves individuals with eating disorders.

www.mentorconnect-ed.org

AED Global Think Tank

2011

In May 2011 the AED Global Think Tank introduced a Virtual Cycle that presents evidence from clinical or practical experience and research evidence as equal contributors to our knowledge base.

A Definition of Advocacy in Australia

Christine Morgan, Butterfly CEO: “Within the Australian culture, advocacy is firmly based within relationship. Without sacrificing its fundamental role of speaking out to change awareness and views, it involves convincing the individual as well as the community. It requires effective relationships with all levels of government and public and private health. It needs to be couched in a way that is heard and responded to. Advocacy is imperative. All eating disorders require early identification and intervention. Awareness is the cornerstone for the illness being recognised, for people feeling safe to seek help, and for appropriate and accessible treatment options.”

Take Home Message

“We must strive to be open to different perspectives, feelings, and needs of respective stakeholder groups and learn to build on our differences. This commitment is central to promoting partnership in treatment and in working collaboratively with one another. Collaboration can bridge the eating disorder, which otherwise grabs at every opportunity to create disconnection within and between patients, families, clinicians, and researchers.” Mary Tantillo, PhD PMHCNS-BC, AED

Challenge: Plan a national forum that brings patients, families, clinicians and researchers together to tap into all resourcing and streamline the bridge from Research to Recovery.

Evidence from Research

Families and Survivors are a vital “Untapped Resource” in the treatment of eating disorders. They have the power to Bridge the Gap between Research and Recovery. Their potential to contribute, together with that of ED support organizations, deserves recognition at all levels.

June Alexander, Survivor & Author: June is testament to the possibility of full recovery. Author of three books, June is a member of AED, ANZAED and is on the board of F.E.A.S.T.

www.junealexander.com

The Butterfly Foundation Claire Vickery, Founder: a mother of two daughters who suffered from eating disorders, Claire founded The Butterfly Foundation in Australia in 2002.

www.thebutterflyfoundation.org.au

F.E.A.S.T. (Families Empowered and Supporting Treatment of Eating Disorders) Laura Collins, Founder: In 2008, a group of parents created F.E.A.S.T., the first worldwide organization to focus on parents and carers of ED patients.

www.feast-ed.org

Maudsley Parents Harriet Brown & Jane Cawley, Co-chairs: founded in 2006 by a group of parents who helped their children recover with family-based treatment, to offer hope and help to other families confronting eating disorders.

www.maudsleyparents.org

Almee Liu, Author: Reclaiming Our Bodies, Reclaiming Our Lives describes recovery through letters. Book proceeds go to the AED, Clinical Research and Scholarship Fund.

www.aedweb.org

The National Eating Disorders Association (NEDA) is a US based non-profit organization supporting people affected by eating disorders.

www.nationaleatingdisorders.org

The Emily Program Foundation The Emily Program Foundation works to eliminate eating disorders through advocacy and education.

www.emilyprogramfoundation.org

Carrie Arnold, Blogger, Science Writer and Author: “Recovering from anorexia, Carrie believes full nutrition is the first step towards recovery. ed-bites.blogspot.com

The Map Ahead In Virginia, on November 3-4, 2011. The aim is to start a new era of science-based, family inclusive Eating Disorder treatment.

www.bedaoonline.com

Kitty Westin, Founder: This Foundation presents evidence from clinical or practical experience and research evidence as equal contributors to our knowledge base.

www.imdfoundation.org

ED Bites Edward Seto, Founder: The Map Ahead is the first step towards recovery.

www.ed-bites.blogspot.com

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www.aedweb.org

Eating Disorders: Critical Points

Aimee Liu, Author:

www.nationaleatingdisorders.org

The Academy for Eating Disorders (Binge Eating Disorder Association) Chevse Turner, Founder: Advocates on behalf of affected individuals and treatment providers.

www.bedaonline.com

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