TELL YOUR STORY

Personal Accounts of Peer Support
Introduction

Peer support helps people cope with and manage their personal and health-related challenges. As a humanizing force in health care, peer support embodies the principles of compassionate, whole person care.

To celebrate the individual and collective impact of peer support around the world, we recently asked peer supporters, program staff, and recipients of peer support to share their personal stories.

In this document, you will find a selection of the stories that we collected. We hope that you will feel as inspired and moved by these stories as we were.

For more information about Peers for Progress, visit us online at www.peersforprogress.org or follow us on Twitter at @peers4progress. This effort was made possible with support from the Bristol-Myers Squibb Foundation.
Gratifying, Rewarding, and Inspiring
Reflections from a Program Coordinator

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Diabetes Queensland
Brisbane, Australia

Diabetes Queensland’s Connect2 Service is a peer support service which links peer supporters (volunteers who have been effectively managing type 2 diabetes for over 12 months) with participants (people recently diagnosed with type 2 diabetes). It is a telephone-based service where peer supporters are recruited, trained, and matched with participants. Peer supporters make regular scheduled calls for up to three months or until participants’ indicate the support received has met their needs.

A greater personal challenge has been balancing the humanistic, empathic approach of peer support encompassing the complexities of human nature, with the structured administrative requirements of running any service.

Coordinating this service and being privy to both participants’ and peer supporters’ experiences has been an immensely gratifying and rewarding experience.

In implementing the service, many practical challenges were overcome, not the least of which was selecting and training suitable volunteers to communicate effectively with participants while maintaining the boundaries of the service. A greater personal challenge has been balancing the humanistic, empathic approach of peer support encompassing the complexities of human nature, with the structured administrative requirements of running any service.

However, these challenges, paled into insignificance when I witnessed the changes demonstrated by participants. For me, the participant quotes below encompass the power of peer support:

“It is not the same conversation [as you have with] a professional. It is a pleasure to talk to someone about the difficulties surrounding diabetes in my life. Out of this type of conversation I got a lot of confidence and motivation and especially I got a chance to get control and management of my diabetes and now I am a person first and then I have the condition diabetes. I am so happy.”
“This is a marvelous concept. [My peer supporter] has helped me enormously with her calm and practical information. It has really made a difference to how I was feeling about the disease and how I might handle it with confidence in the future.”

All participants truly appreciated sharing their experiences with a volunteer who could normalize emotions, and offer empathy and practical suggestions. Participant testimonials demonstrate a sense of empowerment and a marked improvement in perception, motivation levels, confidence, and knowledge. This is reflected in participants’ improved diabetes management, diet, physical activity and interaction with healthcare professionals. Equally fulfilling is the sheer joy peer supporters displayed as participants improved their quality of life. I think this peer supporter quote captures the essence of peer support:

“I wish it was around when I was diagnosed because it would have benefitted me no end. It’s the ability to talk to someone on the same level and not being talked down to and making you think for yourself and not being told what to do. It’s one of the few systems I believe is doing some good.”

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It has been a privilege working alongside peer supporters who so generously share their experiences and provide support and encouragement during difficult times. Their dedication and the resulting contribution they make to improve the lives of others inspires me daily.
With Me Through the Hardest Times
Reflections on the Value of Support Groups

Jim Bundy
Raleigh, North Carolina

When my son had a brain tumor in 1988, he and his mother started going to a support group. This group was founded by a woman with a brain tumor who could not find a support group for people with brain tumors, so she created her own. I did not go - perhaps it was not the “manly thing” to do – but I went one time when my wife could not go, and I have been dedicated to attending support groups ever since. In this support group, I gained knowledge from participants and professionals by listening to how they responded to and handled certain situations. We learned how to live with it, and in our case, how to die with it as our son died in 1992.

The support group showed us that life was possible after losing a child.

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After my son’s death, we joined The Compassionate Friends, an international support group for bereaved parents. It was started in England by a minister who brought two families together after the death of their children to support and help one another. Our mentor, who had lost a son three years ago, guided us through the difficult times, especially holidays, birthday and anniversaries. The support group showed us that life was possible after losing a child. Many members would continue to attend group meetings after they gained some control over the grieving process (although when you lose a child, you never completely recover). For about 10 years, we went to this support group and felt like we were able to help others who were coming in fresh to the grieving process. When we stopped going, we thought our days of support groups were over.

However, in October 2010 my wife was diagnosed with Alzheimer’s dementia (AD). Remembering the previous support groups that had been so helpful and important to our lives, we immediately sought out a support group and found two groups sponsored by ALZNC (Alzheimer’s North Carolina, Inc.). Still today, my wife goes to an activity-oriented support group with 5-6 people who have mild-to-moderate AD, and I go to a caregiver support group with 15-20 people. Through this group, I have learned that tapping into the collective knowledge of the other support group members and the support group leadership is essential in successfully dealing with
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the caregiver/AD relationship. The stories of my group members have taught me how to handle “normal” activities such as dressing, hygiene and eating that become very complex and complicated in the AD world, and they have influenced many important decisions in my life, including our decision to move. Last September, my wife and I moved together to a Retirement Community and plan on staying together as long as possible.

Looking back on the challenges that I have faced within the past 25 years – my son’s brain tumor, his death and now my wife’s Alzheimer’s dementia – it is difficult for me to see how I could have made it without being involved in support groups. They have given me the knowledge, experience and the support that I have needed to keep moving and to make necessary adjustments in my life. Without those support groups, I don’t know where I would be today.
Investing in My Own Healing
Reflections from a Peer Supporter

Natasha Ellis
Canton, Michigan

I am honored to be a part of this essay program. I was so excited because peer support has become my identity and the catalyst for transformation in my personal and professional life. Until recently I could not say I understood the power and impact of one peer helping another until I experienced it myself.

Peer support has become my identity and the catalyst for transformation in my personal and professional life.

A couple of years ago, I went through an episode of deep depression that I could not see my way through, and needed to be hospitalized. On the day I was to be admitted, my therapist arranged for me to meet with the resident peer support and that encounter was my first step to seeing the light. The peer support handled me with such care, professionalism, empathy and best of all, strategy. As he was engaging with me I could see all the techniques we are trained in at work — I realized then that our work is truly from a higher power.

In my work as a peer support the last 8 years I have had the pleasure of managing a drop-in center and that truly was an enchanted experience for me. I created a book club at the center with the sole intention from the beginning of trying to get people interested in reading for leisure or to expand their genres of literature. I wound up changing lives. I started to see one person that if you did not see her, you would not even know that she was in the room. She became more outspoken and willing to be vulnerable because of the book club and the culture we created of love and support.

Peer support is my constant reminder to stay plugged into recovery because when I take care of myself and invest in my healing, everyone I come into contact with becomes a beneficiary.

I have seen people make lifetime discoveries about themselves in our book club, face fears, form bonds, and raise their self-worth. Peer support is my constant reminder to stay plugged into recovery because when I take care of myself and invest in my healing, everyone I come into contact with becomes a beneficiary.
The people in my hometown of Louisville, Kentucky, call me “that neuropathy lady.” Fifteen years ago I was struck with a life-threatening form of peripheral neuropathy (PN), which has almost claimed my life several times. When I was first in intensive care, unable to breathe or move on my own and in constant pain, I promised myself that if I was able to, I would start a support group for this terrible condition. Since that day, I have helped thousands of people worldwide, including hundreds of people locally. I have been on TV shows and radio, organized several large symposiums, written dozens of articles, and spent many visits with PN patients. I have worked hard at spreading awareness about this mostly-unknown condition and how it affects those who suffer with it.

Being the “mother” in my support group has helped me achieve many wonderful accomplishments. I have formed many beautiful friendships that I know will last forever. Being able to help PN patients has actually helped me get better myself. There isn’t a better feeling in the world than when a person says to you, as a gentleman recently diagnosed with PN said to me last night, “You have given me the first hope I have had in six months.” Once I went to sit with a young girl who was getting her first infusion of a medicine that can help a form of PN. I held her hand as she got the infusion and talked her through it. Her mother then took me outside and said “We have been praying for God to send us an angel. He sent you.” My dinners and favorite TV shows are often interrupted with calls from new patients – but I value each and every call.

I also volunteer and help with other conditions, too. I started another support group for a condition I have called myasthenia gravis. Recently I recovered from thyroid cancer, and I am now volunteering for the Friend for Life Cancer Support Network in Louisville. Two weeks
ago I gave a presentation to this group on PN, as many cancer patients get PN from their chemotherapy treatments. This has opened up a new avenue for me to help PN patients, and I am eager to help as many of them as I can.

Peer support has given my life a meaning that I might not have found otherwise. After all of these years of doing this work, I have decided that I was chosen to get this disease so I could help others get through it. I believe this is my calling, my reason for being here. Because of this, I would not change what has happened to me. Indeed, I embrace it, because this has given my life a meaning that I might not have found otherwise. If I have any words to share with other people who suffer with any medical condition, they are to help others with your disease, and you will help yourself. You will find a greater understanding of the value of life, and enrich your own in the process.