Talking in Private: Facebook Closed Group Promotes SCI Peer Support



YOU ARE NOT ALONE When Coping With A Spinal Cord Injury



Facebook recognized the success of our Closed Group and invited us to lunch with Sheryl Sandberg, Chief Operating Officer of Facebook.

Pictured at left: Sheryl Sandberg, COO of Facebook, with Stephanie Lollino, Executive Producer at the Hill Foundation and Administrator of the FacingDisability Facebook group.

www.facebook.com/groups/FacingDisability

Objective: Facebook community groups are playing an ever-larger role in daily life. Facebook reports that over 600 million groups have been formed in the past decade. Facing Disability.com, a website that contains more than 2,000 videos, is a gateway to healthcare information from spinal cord injury experts and to the life experiences of families coping with spinal cord injury. Facing Disability.com created a private group on Facebook with membership limited to those with traumatic spinal cord injuries and their families. People with SCI have a continuing need to build resilience with connections to others like them. This poster presents data showing how the Facing Disability.com Facebook group, "You Are Not Alone — Dealing With Spinal Cord Injury," promotes communication among people living with SCI.

Design/Method: On February 1, 2017, Facing Disability.com launched a private (closed) group on Facebook. A closed group is a place where approved members with specific interests can gather and speak openly — without their usual circle of friends reading along. None of the subjects discussed can be seen on a non-member's newsfeed. Members were added to the closed group only after answering a series of screening questions specific to spinal-cord-injured individuals (for example: "If you have a spinal cord injury, what is the level of your injury?"). Facing Disability.com promoted the private group to potential members in emails and its monthly newsletter and purchased Facebook ads targeted to the SCI community. Within eight months the group had more than 2,000 members. Within a year the number had grown to more than 3,000.

Results: Reports generated by Facebook Analytics offer detailed insights into group membership and engagement. Current members range in age from 18-65+. The age range 25-64 accounts for 82% of members. Women constitute 59% of members. Most members (80%) live in the U.S. Members "engage" (post, comment or react) about

equally throughout the week, with Mondays and Wednesdays being slightly higher; most popular times are before lunch (11:00 am) and before dinner (5:00 pm).

More than two out of three members (67.5%) engage with the group every week; slightly more than half (51%) engage with the group every single day.

What are they talking about? The posts with the highest engagement rates are about sex and finding love, caregiving, rehabilitation, and medical complications, such as autonomic dysreflexia, UTIs and pressure ulcers. Personal experiences with baclofen pumps, different types of catheters and wheelchair problems are shared daily.

The tone of all posts and comments is almost uniformly serious, sympathetic and helpful. For example, more than half the group (1,100 people) reached out to encourage a newly injured teenager (C7 quadriplegia) to let her know she is not alone. More than 800 people responded to a man who wrote about how his service dog had improved his life and attitude "immeasurably." Almost 900 people responded to a young man who asked: "How do I find a woman who will be with me now that I'm paralyzed?"

Conclusion: Facebook closed groups can provide a peer community that offers valuable support for people coping with spinal cord injuries.

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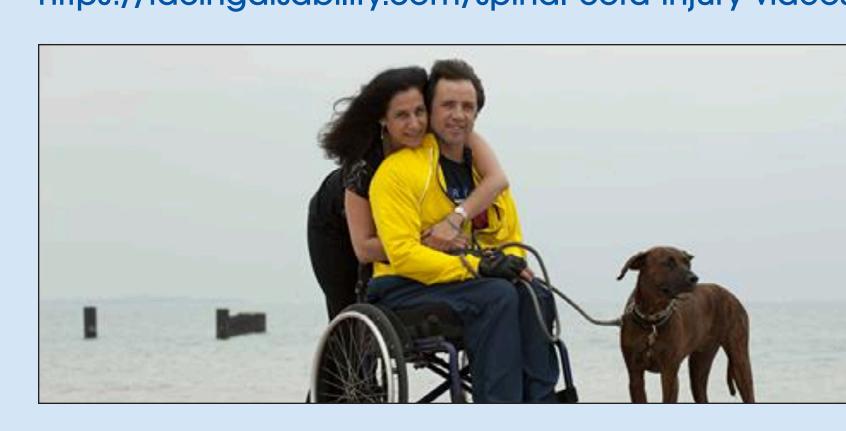


Sample Conversations from Group



Welcome to the FacingDisability.com Facebook support group. We are so glad you found us. This is a place to discuss everything and anything related to living life with paralysis. We ask that nothing be sold or traded in this group or in its posts.

See our vast video library of individuals and medical professionals answering questions on topics people with paralysis deal with every day. For MUCH more on spinal cord injury (SCI), visit:





So I'm just curious. How long after your spouse's accident before intimacy was back to a somewhat normal place? My husband is c5,6&7 and is still just so depressed that he is very withdrawn in that area He says he desires sex but gets frustrated with me

10 Likes 50 Comments

Luigi Describe the word "still". How long has he been

Karrie Just since August

Luigi You have to let him sort things out. He will figure it out eventually. Time is everything.

Tom Patience.... I know it is very hard to be caregive and wife and working full time, but in his mind he feels he has lost this life, he don't know what is happening with his body, when a man loses his self and his sexual function it is tough, he lost everything, and he feels that he might be losing you. Give him time.

Scott I'm 8 years post with a T7 incomplete. What's sad is that the way Society is now days makes a mar feel like he is less of a man because he can't put out. I can't speak for a woman, but with a man with SCI it's more of a mind thing and being able to touch. One thing about it is you learn to enjoy it more.

Tim I didn't have sex for a year after I was paralyzed I was dealing with constant UTI s for a year. We finally got that under control. I talked with the urologist and they prescribed Sildenifil for erections. But I like you would just like some closeness. To feel like a man. God bless you guys. I would be patient but considtalking to urologist



Hello group I'm a T11 been 9 months since my accident. I checked myself today and I noticed that that my skin is breaking down a little. And before y'all say anything - I don't do my weight shifts like normal but anyway, what is there I can use to treat it before

it gets too infected or spreads? Any advice will help. I've put some Vaseline on it but the place of concern is just above the buttocks - above the crease.

Carla No Vaseline! Get antibiotic ointment try and stay off that area as much as possible. Do weight shifts or you'll regret it. If it gets red, swollen, pain or hot go to Dr. ASAP

Melissa Go to the drug store and get fanny cream. Druggist has to make it. You need the zinc. Stay dry

Hannah Rick my fiancé had this at the start before we realized his commode cushion was too big so his cheeks were stretched out when on the toilet and in the shower. Try to get a smaller cushion and sleep in your side at night. We used pawpaw ointment until it healed and put over the top waterproof bandages.

Mike I can't stay off mine. Swear by the Allevyn

Marty Yep first thing is not get a pressure sore a good cushion should do it. I've used a Roho high profile the last 27 yrs. I'm a t 10-12 complete para



Here is an somewhat unusual request. My son, a para, T-4 complete, 3 1/2 years in. Abandoned by so called friends, almost been scammed twice by unscrupulous people online, pretty lonely. I will admit he has way too much time on his hands, doesn't work or go to school. But is slowly getting there..

I'm not even sure if I should be asking this...but.. Can any of you friend request him? Just be a pen pal friend? I've suggested this group to him because who knows this affliction better than this group?

38 Likes 210 Comments

Nancy My daughter is the same age and the thing that helped her the most was doing some adaptive events. Surfing with life rolls on, sailing at an adaptive boat club, indoor sky diving and going to the abilities expo near us. She met so many people that are in different phases of their wheeled journey. It motivated her to get her license and go back to school.

Rob Was he athletic before injury? Even if not, trying different sports can be a spark to get out of depression. I wasn't athletic at all, but I tried every sport that I could find (basketball, lacrosse, rowing, softball, sled hockey, tennis, etc.) I fell in love with tennis and it really boosted me out of it. It also connects you with a great group of people.

Michele I am a T 5-6 incomplete. 18 years post injury. I would be glad to be a pen pal to your son.

Paul I feel I have to comment on this. I'm 28 years old, I I grew up in the U.K. foster care system and eventually thrown into children's homes. I have no family at all!! When I got injured I woke up alone after surgery. I was in rehab for 8 months and in that time, I had 4-5 visitors. Trust me when I say I'm an expert on being lonely. Tell your boy he can send me a friend request whenever.

Note: Last names have been removed and profile images blurred to protect the privacy of members.