



Appraisal

Media: Facingdisability.com: a unique video library reflecting the experiences of people with spinal cord injuries and their families

Background

Spinal cord injury (SCI) affects not only the lives of those who are injured but also the lives of their families and caregivers. Sharing life experiences with peers and peer support are both common following SCI and are thought to enhance well-being and self-efficacy in people with SCI and their families.¹ This is in line with the World Health Report on Disability that recommends 'people with disabilities and their families can support other people with disabilities through peer support, health information and advice'.² Evidence about the best way to provide this information and support is still emerging; however, commonly used methods for sharing life experiences and providing peer support include websites and Facebook chat groups.³ This review appraises one such website: Facingdisability.com

Origins of the website

Facingdisability.com was launched in 2011 by the Hill foundation: a not-for-profit organisation in the United States of America (USA). The website was established following the positive experience of one family whose daughter benefited from peer counselling following her SCI. For this reason, the founders were motivated to establish a website that offered education and peer-support not only to people with SCI but also to their families.

Content on the website

From the home page it is easy to navigate to the different layers of content. The content includes: videos sharing the lived experiences of people with SCI and their families; videos of interviews with SCI experts; general information about SCI; a blog; links to useful resources; and a closed Facebook group.

The video library of over 100 people with SCI or their families is a highlight of the website. The videos present diverse perspectives on 48 questions across 13 important topics for people with SCI. Usefully, these videos can be filtered by type of injury, relationship, age and gender, or browsed by topic. While many videos of people with SCI exist on the Internet, these videos stand apart because they are concise, of high quality, and contain both the perspectives of people with SCI and their families. The video library of interviews with experts (including physiotherapists) working with adults and children with SCI is equally impressive and provides credible information for families. The interviews with experts that treat children with SCI provide unique insights that are not easy to access outside the few specialist centres that treat children with SCI.

The general information pages about SCI are necessary and engaging. On occasion, accuracy has been compromised for simplicity and accessibility. For example, the description of incomplete and complete injuries is not strictly correct as per the widely accepted definitions provided by the International Standards for Neurological Classification of Spinal Cord Injury.

The 'Join the conversation' tab invites people with SCI and their families to connect with peers through a closed Facebook group. This

Facebook group is moderated by the website and can only be accessed by people with SCI and their families. An example of the type of conversations that occur within the group is provided on the website. The Facebook group and how to join is clearly described on the website. The website mentions a peer counselling service in the 'About' and 'Media' tabs; however, this link takes the user to the Facebook page so this aspect of the website may have been superseded.

Key strengths

The website is very easy to navigate on a variety of devices, including tablet, PC or smartphone. It is beautifully produced with high-quality videos and sound. Importantly, the resource is free and the website contains no advertisements. The most unique contribution of the Facingdisability.com website is that in addition to assisting people with SCI, it also helps families. Resources for families of people with SCI are clearly important but not widely available.

Limitations

The website has one key limitation: it does not capture the perspectives of those living outside the USA. To increase worldwide appeal, videos of individuals across continents would be ideal. Interestingly, the Facebook group is open to people with SCI and their families from across the world, although presumably it is only useful to those who speak English. Perhaps the global nature of the Facebook group will provide opportunities for the website to link in with people experiencing SCI in countries other than the USA.

Summary

Physiotherapists and physiotherapy students are an integral part of the team working in partnership with people with disabilities. Listening to and understanding the diverse opinions and perspectives of people with disabilities and their families is essential for these partnerships to be successful. For this reason, Facingdisability.com is not only useful for people with SCI and their families, it is also a great resource for physiotherapists and physiotherapy students.

Provenance: Invited. Not peer reviewed.

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References

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