

Support for the social and emotional effects of EB

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The views of some adults with EB

- Interviews with 24 adults who have EB about how the condition affects their lives
- Support that could help social and emotional wellbeing in the words of people with EB

An important message

- ***“Everybody is different, everybody’s individual, and you can’t say anybody is right or wrong you just have to say ‘well that’s what works for them’” (Neil)***
- Different people need different kinds of support at different times in their lives

Readily available information

- ***“There is a lot of info on children with EB freely available but not much for the teenagers and adults. Also, not much for the non-EB people to take a look at and understand it. It’s all very EB focussed on what to do if YOU have EB and what to do for your child who has EB but there is lacking info for friends/ partners with EB friends/partners.” (Josie)***
- Provide information written in a non medical way about relationships and friendships

Peer support

- ***“I think what people need is a mentor, someone that’s been, an older person who has been through that, that would be most useful to me” (John)***
- Give people the chance to talk to someone with similar experiences who understands what life can be like

On-line communication

- ***“Services I would like to see set up or available is somewhere young sufferers can meet, like a chat room or regular meeting other than in a hospital environment.” (Becky)***
- Make it easier for people to get to know each other, for example using real time chat rooms

Help people to self manage their EB

- ***“I’ve upset tens of doctors over the years but...it’s my body and I know what’s best for it...and if that upsets them it’s tough, I don’t set out with the intention of upsetting them, I set out with the intention of making them aware of what’s right for me” (Craig)***
- Give people the information and confidence to look after themselves and be assertive with others

Someone to talk to

- ***“I think you feel really depressed and I think what makes it even worse is, there's no one you can actually go to, to turn around and say how you feel” (Steve)***
- Provide the opportunity to talk to a trained person when negative emotions take over

Helping parents

- ***“I felt I could have had another dimension to my life rather than... other than you know just this EB business and the blisters, but it was so traumatic for my mother because she didn't have any help”***
- Support parents to make life as ‘normal’ as possible for their children with EB

Your opinion

- What kind of things would help you, your family, and your friends, socially and emotionally?