

DEBRA: promoting a holistic model of care

DEBRA, the national charity that supports individuals and families affected by Epidermolysis Bullosa (EB), provides a nationwide EB community support service to help people with the condition overcome the challenges of their everyday lives. The effects of EB go beyond medical care of the skin, and can require a range of practical and emotional support. DEBRA's EB community support managers see the effects of EB first-hand and collaborate with healthcare teams around the country to provide holistic care and support to people living with the condition.

DEBRA's EB community support team works closely with specialist EB nurses and other health and socialcare professionals, regularly attending EB clinics at each centre of excellence for EB as well as local outreach clinics. In this way, people living with the condition can receive support for a range of medical and social issues at the same time.

THE ROLE OF DEBRA'S EB COMMUNITY SUPPORT MANAGERS

EB is very challenging to live with — it affects individuals and their families in many different ways. DEBRA's EB community support managers provide advocacy, helping to articulate how EB may affect people's ability to function, their housing, work and leisure needs, facilitating better access to housing, social services, schools and workplaces. EB can also take its toll financially — DEBRA's EB community support team is able to provide high-quality information on benefits available, give assistance with filling out complex forms, attend tribunals and help to appeal benefits-related decisions. In times of extreme need, DEBRA also gives support grants towards the cost of equipment or services that relieve physical and psychological stress and facilitate safety, enhancing the services provided by the NHS.

Living with EB or caring for someone with the condition affects the whole family and carers and family members are helped by DEBRA's EB community support managers to access local services specific to their needs. Participating in social activities can also present extreme physical challenges for people living with the condition. To



Living with EB or caring for someone with EB is very challenging. Patients and carers need a lot of support

tackle the issue of isolation DEBRA also provides peer support by offering opportunities for people with EB to share their experiences with others living with the condition. DEBRA is also there to help at the very difficult time following the death of a loved one with EB, conducting joint home visits with specialist EB nurses.

TESTIMONIAL ABOUT DEBRA'S EB COMMUNITY SUPPORT MANAGERS

"Our DEBRA EB community support manager and our specialist EB nurse [part-funded by DEBRA], were able to work very closely together and help us," says one parent of a baby with EB. *"Our community support manager has attended hospital appointments and even home visits where she has been able to translate for us. We have faced many difficulties but she has helped us cope with a big one – the language barrier.*

Our specialist nurse has been wonderful, going beyond the call of duty to make sure our son gets the care he needs. We had difficulty obtaining the right dressings for him on prescription and she spent a lot of time on the phone explaining EB to our GP ... to make sure they really understood his needs.

DEBRA has enabled us to understand the complicated and confusing health and social care systems. Our Community Support Manager has helped us with our applications for tax credits and disability living allowance for our son, as well as signposting us to other organisations for support with things like immigration. We've also received a support grant to purchase essential items. I honestly don't know how we'd manage without DEBRA."

WUK

Further information

If you would like more information on DEBRA or EB, or if you are interested in attending a course or study day, please visit: www.debra.org.uk/healthcare-professionals

debra
for people whose
skin doesn't work
we do