



***The benefits of home nursing support in lessening the impact of EB care on the family unit***



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*“During early childhood difficulties with bandage changes will undoubtedly develop, as it often hurts and takes a long time. Pain and discomfort can cause anxiety for the child and the parents. The feelings of helplessness and being at the mercy of someone can anger a child with EB and drive him or her into a rage which may be very difficult to manage. Advice and support is necessary during this particularly difficult period of life.”<sup>i</sup>*

Dr Anja Diem – Manager of EB Outpatient Unit at EB Haus Austria

**Epidermolysis Bullosa (EB)** is a very rare genetic condition in which the skin and internal body linings blister at the slightest knock or rub, causing painful, open wounds. In order to protect the skin and prevent infection it is necessary for patients to wear dressings on their bodies at all times. For patients with severe EB dressing changes are a long, grueling and painful procedure during which all blisters are burst and drained, ointments are applied and the skin is wrapped in up to three layers of dressing. A recent survey of severe EB patients, conducted and published by Lotus Tissue Repair, in the United States, stated that bandages are changed on average 6.4 times per week and that the process takes approximately 2 hours each time (publication in preparation). 80% of patients surveyed were on strong pain medication, such as oxycodone or morphine, for the pain which is at its most acute during the process of changing bandages. In Ireland, dressing changes are undertaken almost exclusively by parents and other family members, a situation which makes an already difficult condition all the more distressing for all the family.

According to Dr Anja Diem, a specialist in EB who is currently based in Austria: “it may not be physically possible for parents to always provide the most optimal wound care, following a sophisticated care plan, every day of the week, given the other issues and conflicts that may at times arise.”<sup>ii</sup> Parents can learn the technical aspects to wound care but it is impossible for them to maintain the emotional distance necessary, in a situation where clinical care involves the infliction of pain. Putting one’s own child through such horrific pain is incredibly difficult and a huge emotional drain.

In addition, caring for a child with EB places many other stresses on the family unit. Parents often find it extremely difficult to juggle caring for their child with EB and caring for their other children. It is not uncommon for parents of severely affected children to focus much of their daily efforts toward their care. As a result, “about 25-50% of all EB parents expressed a feeling that they sometimes neglected their other children because of the pressing needs of their affected child”<sup>iii</sup>. Naturally, this puts a strain on familial relationships. A condition like EB has an untold effect on all members of the family unit. According to the Women’s and Children’s Health Network, “relationships within the family will be altered, and sometimes strained, as everybody adjusts to the situation and takes on additional responsibilities. Sometimes other children get a lot less time and attention.”<sup>iv</sup> Jo-David Fine, an American dermatologist and EB expert has noticed that with increasing age, “some unaffected children may also have to assist in caregiving for their affected siblings, especially following divorce of the parents, further limiting or restricting their own day to day activities.”<sup>v</sup>

In some other countries, such as New Zealand and the United States, home support nurses are becoming the norm and this is positively impacting the outlook for families living with EB. In the United States, such nurses are paid for by private health insurance. In New Zealand the posts are jointly managed by the National Health Board and DEBRA New Zealand. "The general opinion in New Zealand is that parents of EB patients should not be directly involved in the changing of gauzes and bandages every day,"<sup>vi</sup> and dressing changes are being performed less and less by parents and more and more by specialist EB nurses who travel the country and also by local home support nurses. In New Zealand there are currently five patients who need this high level of care in the home.

#### **Case study: 29 year old Humphrey Hanley from Wellington, New Zealand**

Humphrey Hanley, an EB patient from New Zealand, gave an inspirational speech at the DEBRA International Care Congress 2011 in Groningen. He gave a heartfelt account of the positive changes that occurred in his life, once his parents stopped doing his dressing changes and became what they should have always been; simply his mum and dad. He spoke of how, for a child growing up with EB, "the care, love and protection shown by parents can often feel more like torture, suffering and pain." He recalled "screaming the house down" every night and was adamant that parents should not have to "come at you with a scalpel every night and pull at your skin". When Humphrey was 7 years old, he and his parents began to attend family therapy with a well-known practitioner named David Epston<sup>1</sup>. David Epston had worked extensively with families where at least one child suffered from a chronic illness and he had noticed that when parents stopped allowing the condition to dictate all aspects of family life and were permitted to focus a little less on their child's clinical care, the child often got remarkably better. Humphrey went on to illustrate how his own health substantially improved once his parents received the nursing support that they desperately needed and could remove themselves from dressing changes. He feels that he would not be the happy, confident and independent young man he is today had it not been possible for them to segregate EB from family life and make the shift away from him being dependent on his parents to change his dressings daily.

David Epston worked with a number of EB families and got close enough to them to see for himself the trauma caused by parents performing dressing changes every day. Writing about the first time he saw a dressing change taking place he said: "There was no way whatsoever I could have been prepared or could have prepared myself for the prospect of parents being obliged daily to act towards their children in ways everyone knew was inflicting excruciating pain. Young children could not be expected to mediate such sensations into dignified suffering. The pain was just too painful to be distinguished as benevolence or care. It is felt to be as painful as

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<sup>1</sup> David Epston is a New Zealand therapist, co-director of the Family Therapy Centre in Auckland, New Zealand, and Visiting Professor at the John F. Kennedy University. Epston and his late friend and colleague Michael White are known as the originators of narrative therapy.

intentional torture.”<sup>vii</sup> This could not but have had an extremely negative effect on the relationship between parent and child. Central to David Epston’s theory on the handling of EB care is the idea that when the parent is not in charge of wound care the child begins to see themselves as a normal person who just happens to have EB. EB is no longer the central tenet of the most important relationships in their world. Anna Kemble, Humphrey’s mother, feels that it was her separation from Humphrey’s illness that inspired his “evolving sense of identity, self-confidence and independence.” David Epston told DEBRA Ireland that in some cases dressing times went down by up to a third when a third party took over. He also said that it is believed by many that severe EB patients in New Zealand have a 40% better quality of life than in other comparable countries, such as Ireland, due mainly to this crucial difference.

EB community in New Zealand are at the forefront when it comes to keeping treatment separate from every day life, ensuring that the patient and their family have some degree of normality in their lives and distance from the illness. They have also devised the concept of bandaging rooms, specifically for the purpose of performing EB dressing changes.

“A ground-breaking New Zealand EB initiative has been the design and use of separate purpose-built bathing and bandaging rooms. The room ensures the bandaging process is kept as sterile as possible, with the shower, bath and toilet used only by the person with EB. Storage hides away the many boxes of bandage supplies, food supplements, and hospital linen. Home-based care plans with these facilities avoid unnecessary hospital admissions. Wellbeing of the whole EB family unit is maximised. Very significantly this facility allows home to be more of a normal family home, with the ‘un-fun’ painful EB stuff moved to the sideline, confined in its own territory well away from the child’s bedroom and the family living spaces. The focus is on well being and normal family life, subtly minimising EB’s impact.”<sup>viii</sup>

Unfortunately detailed studies on the impact of parents being responsible for dressing changes have not been undertaken. The anecdotal evidence in favour of an external care-giver taking this role is compelling however. We need to move towards a model of care for families living with EB which is more holistic in nature, not only focusing on the immediate and pressing physical needs of EB patients but also considering the psychological aspects of the condition and respecting the impact of EB on the family unit.

Having an outside caregiver take over dressing changes from the parents will not be without its challenges. It requires the building of trust on behalf of the family and the building of knowledge and expertise on behalf of the care-giver. Once established however, we believe the potential for a positive and long-term impact on the patient and their family is immense. Some parents may opt to continue undertaking dressing changes themselves, finding that this option is in the best interest of their family. It is our strong belief however, that all families who live with severe EB should have a choice – a choice on whether or not to continue undertaking the long, grueling and

painful procedure of dressing changes or whether to hand this aspect of EB over to a professional care-giver.

For more insight into what is involved in EB dressing changes see this excellent, short YouTube video: [Garrett: The boy Beneath the Bandages](#)

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<sup>i</sup> Diem, A. (2009). 'Living with EB – Impact on Daily Life' In J. Fine & H. Hintner (Eds.), Life with Epidermolysis Bullosa (EB) (pp.313-333). New York : SpringerWien

<sup>ii</sup> Ibid.

<sup>iii</sup> Fine, J. (2009). 'Psychological and sociological aspects' In J. Fine & H. Hintner (Eds.), Life with Epidermolysis Bullosa (EB) (pp.204-208). New York : SpringerWien

<sup>iv</sup> <http://www.cyh.com/HealthTopics/HealthTopicDetails.aspx?p=114&np=304&id=2578>

<sup>v</sup> Fine, J. (2009). 'Psychological and sociological aspects' In J. Fine & H. Hintner (Eds.), Life with Epidermolysis Bullosa (EB) (pp.204-208). New York : SpringerWien

<sup>vi</sup> <http://debracongres2011.com/45.html>

<sup>vii</sup> <http://www.dulwichcentre.com.au/co-research-david-epston.html>

<sup>viii</sup> <http://www.debra.org.nz/projects-research/eb-bandage-rooms.html>

