

Dear valued member of an Ectodermal Dysplasia Parent Support Group,

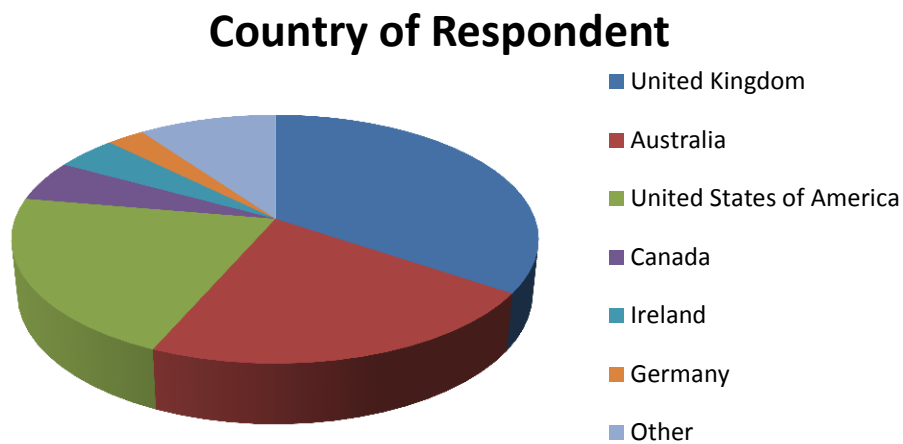
Thank you for your participation and cooperation with our online survey in 2012. Thank you also for supporting our research by allowing your members to complete our online survey and ensuring that the survey was promoted and disseminated amongst your members to complete.

The results from the survey has made an enormous contribution to our understanding of the supportive care needs of parents caring for a child with ED, and has already provided us with some insights into important issues. Our survey received responses from Australia, Bangladesh, Belgium, Canada, Germany, India, Iran, Ireland, Occupied Palestine Territories, Poland, Slovakia, South Africa, United Kingdom, and the United States of America. We had responses from 126 parents, which considering the rarity of ED, absolutely amazed us.

We have already written and submitted two scientific papers based on the results of our survey, and would like to provide you with a summary of some of these results for your interest.

Respondents

Nearly all respondents (92%) were mothers, with ages ranged from 15 to 66 years. The pie chart below shows the countries that respondents came from.



One quarter of parents (25%), stated that they themselves had been diagnosed with ED. Of these parents, 69% said that they had been diagnosed as an adult. In the majority of cases (86%), this was following their child's diagnosis.

Most respondents (85.7%) had a single child with ED, however several had two (10.3%) or three (2.4%) affected children and two respondents had four.

Diagnosis

Early diagnosis of ED in child

As we anticipated, parents in the survey confirmed that receiving an **early diagnosis** of ED in their child is indeed important to them. They informed us that the period leading up to diagnosis was stressful, and that it was a complex and protracted process which relied heavily on them as parents to facilitate.

“Very important because it explains so much of what is happening to the child and how to treat it, whereas in my case, I was left for about 15 months with not knowing about why my child was going through so many different medical things at once”. (Australian mother aged 34)

The majority of parents (68%) were concerned about the long-term health and wellbeing of their child in the period leading up to diagnosis. Respondents also observed that clinicians relied heavily on the key physical characteristics of ED, such as, dental abnormalities to be present in order to make a definitive diagnosis.

According to most parents, their primary source of information and education about ED came from an ED support group and the internet; but only once a diagnosis was achieved.

Parental guilt, blame and regret

Nearly all parents (92%) recalled experiencing at least one type of powerful emotional response, either negative or positive to receiving a definitive diagnosis of ED in their child. The most common negative emotions experienced were guilt, blame and regret.

“I was upset, wondering why, what had caused it, if I was to blame as I had been ill during the pregnancy? Nobody seemed to know much about ED then. No idea about what the future held or how hard life would be for our son”. (UK mother aged 39)

The equivalent positive response to receiving a definitive diagnosis was relief. For a number of parents they experience positive and negative responses to diagnosis in union.

“We felt relieved, that we finally had answers and we were vindicated for being so vigilant with their crying and listlessness. Before diagnosis we were called weak and overprotective parents”. (Australia mother aged 41)

Breastfeeding difficulties

Breastfeeding complications are an unexpected phenomenon which we discovered from our research and one whereby a dearth of literature currently exists.

Nearly half of all mothers who responded to our survey (44%) said that they had experienced difficulties breastfeeding. When we compared breastfeeding difficulties between mothers who have ED with mothers who do not, there was a consistent pattern of mothers with ED having experienced greater difficulties with regards to breastfeeding.

Mother specific problems associated with breastfeeding included;

- lack of milk supply
- pain and discomfort with feeding
- baby took a long time to feed
- baby attachment issues due to breast abnormalities i.e. hypoplasia
- baby unsettled following a feed
- loss of breast tissue in mothers who persisted with breastfeeding for a period.

Our survey results support similar findings from a survey conducted by NFED; Jill Powell and Mary Fete, 2012.

Parents in our survey describe their breastfeeding experience as an emotionally traumatic experience and felt judged and unsupported by the midwives and lactation consultants. Many of these mothers said that for a time they felt as though they were a failure and a ‘bad mother’.

In relation to child problems and breastfeeding, 67% of parents who completed this part of the survey said that difficulties only occurred in their child with ED.

The immediate and long-term implications of these difficulties in mother carriers of ED are not well documented in the literature. Our research has highlighted a need for more in-depth investigation. As of this year, we are now starting to delve into this supportive care issue to determine just how significant breastfeeding is in mothers and children with ED is.

Parenting

From our survey, there were a number of supportive care issues that arose with regards to parenting a child with ED; these included relationship impacts between partners/spouses, impacts between siblings and parent reproductive decision making and family planning.

Impact of ED child on partner relationship

In all, around 36% of parents who responded to our survey said that they felt parenting a child with ED has had an impact on their couple relationship. There were both positive and negative responses. Some parents said that they found the daily struggles to cope with and care for their child with ED to be exhausting and they had little time or energy to invest into their relationship with their partner. Other parents said they this daily challenge resulted in separation from their partner.

“Our son is complex and demands a lot of care. He sleeps in our room because I need to position him all night. I’m too tired to give our marriage the attention it deserves”. (USA mother aged 31)

Conversely, other parents responded more positively. Some felt that the challenges and hurdles encountered with parenting a child with ED has brought them closer as a couple and has strengthened their relationship.

“It has put our marriage under a lot of pressure and caused many arguments, but we’re probably stronger now 3 years later”. (Ireland mother aged 30)

Impact of ED child on other siblings

The parents in the survey (59%) felt that having a child with ED had both positive and negative impacts on the other siblings. The most common negative impression voiced by parents was that they simply did not devote enough time and attention to the other siblings. Countless hospital visits and medical appointments often resulted in the siblings missing out on their own activities and were expected to tag along.

Parents also commented that there were many times when they would have to prioritise the needs of their child with ED over the needs of the other siblings. Planned family outings or activities more often needed to be centred on the limitations of the ED child than on what the whole family would enjoy.

“I have a 15 year old daughter that goes to the same school as her brother with ED and she also receives teasing for his condition. As a child she was impacted by a huge lack of attention as her younger brother was hospitalised so frequently and for extensive periods, leaving her to learn how to amuse herself”. (Australia mother aged 45)

Conversely, for some of the parents in the survey, their impressions of the impacts were distinctly positive. They observed a special and unique bond form between the siblings and child with ED. Some parents even went so far as to say that having a child with a condition as unique as ED has given the other siblings a realistic perspective and acceptance of others who are different to themselves.

Reproductive decision making and family planning

Another phenomenon that was not previously identified in the literature was reproductive decision making and family planning. For nearly half of parents surveyed (44%), a decision not to have further children following their child’s diagnosis of ED was identified. Parents felt that they did not want to risk another pregnancy, that they were scared that the next baby would have ED and that the symptoms might be worse.

“We were not sure what she had for several years. Then when we were told there was a 25% chance of it happening again, we were scared to have more children”. (USA mother aged 37)

Some parents surveyed, felt it would be wrong to have another child that might suffer with the symptoms that their current child with ED has.

“Our ED child is a boy; he was diagnosed while I was pregnant with my daughter. If I wasn't already pregnant, I would never have risked another pregnancy”. (Canada mother aged 29)

Social support

Responses from the survey which focused on social support identified that parents prioritised two main areas of support; family and specialist support.

Expectedly, the majority of parents in the survey said that their primary support came from within the family; their partners (61.1%) and other family members (55.5%), followed by internet sites (31%). It was clear from the survey results that the majority of respondents and their partners were jointly attentive to the support needs of their child with ED.

In regards to specialist support, respondents were asked to rate their level of satisfaction with specialist support. More than half (53%) were satisfied with the support they received. However, when asked whether they would have liked more support, 75% said that they would.

An underlying support theme which emerged from the survey was that parents voiced a need to feel socially connected with and supported by others that are understanding and can empathise with their unique disease experience.

“I am satisfied and unsatisfied. The dental specialists have been fantastic. However, ED is a mixture of affected structures and needs to be treated as a whole. The relative specialists need to communicate with each other and link back to my local doctor. Apart from what I have told my local GP, she does not have any idea of the medical care our son is getting from other specialists”. (Australia mother aged 44)

Our study and its findings help to narrow the knowledge gap in the area of supportive care of parents caring for a child with ED, especially in the first few years of their life. In reality, we have only just scraped the surface into what it is that parents require regarding support in areas such as social and specialist support, obtaining definitive diagnosis and family planning and decision making.

Of note, our unexpected findings regarding breastfeeding difficulties in mother carriers of ED is an area which we are currently investigating at a much deeper level.

There is comparatively little research into ED, and almost none in the area of the psychosocial needs of parents with a child with ED, or for that matter, parents who themselves have ED. This is a wonderful opportunity to greatly enhance our understanding of this rare condition.

We would very much like to keep in touch with you and collaborate with you over the coming years regarding further research into the psychosocial needs of parents. We will be contacting you in the near future to ask you some further questions that have emerged from the findings of our original survey.



Thank you.

With kind regards,

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