



Evaluation of CEN Emotional impact of tube feeding project (2010-2013)

Aims of the project

- Increase awareness among professionals of the emotional impact of changing from oral feeding to tube feeding
- To improve support for families when their child changes from oral feeding to tube feeding
- Develop a CEN DVD showing interviews with parents and professionals and a CEN patient leaflet and make these available to families and professionals



Baseline (January 2010)

42 parents completed the CEN Survey about tube feeding in January 2010.

- In January 2010 73% of the parents whose child changed from oral feeding to tube feeding before 2010 did not receive emotional support. 20% mentioned some emotional issues were discussed and only 7% reported they received a lot of support when their child changed to tube feeding.
- In January 2010 parents suggested the most important improvements would be to acknowledge that the decision to change to tube feeding may be upsetting and to have a leaflet about the emotional issues relating to tube feeding.

Approach (January 2010 - January 2013)

The National Managed Clinical Network for Children with Exceptional Healthcare Needs (CEN) discussed the emotional impact of changing from oral feeding to tube feeding with the service users group of the network. The parents agreed improving support for families was a priority. CEN commissioned Claire Edwards, a training consultant and parent of a child with additional needs to interview parents and professionals and develop a DVD (Feb 2010). The CEN Service Users working group and CEN Education working group developed a patient leaflet about the emotional impact of tube feeding (Dec 2010).

The DVD was shown at the CEN tube feeding conference (Feb 2010) and used at over 30 training events, national and international conferences.

Over 1700 copies of the DVD and 1100 copies of the patient leaflet have been requested and sent out. In addition, the DVD was viewed over 1500 times on the CEN website.

Outcomes (January 2013)

51 parents completed the CEN survey (October 2012-January 2013), 13 discussed their child changing to tube feeding before 2010, 38 discussed their child changing to tube feeding in 2010-2012.

In this report we discuss the impact of the CEN project and therefore we focus on the experiences of the 38 families in 2010-2012.

- In 2010-2012 26% of the parents reported that they received a lot of support when their child changed to tube feeding, 26% reported they received some support and 48% of the parents reported that they did not receive emotional support when their child changed to tube feeding.
- The highest level of support was reported by parents in 2010. In 2011 and 2012 the emotional support was slightly reduced.
- 3% of the parents reported they did not talk about the emotional impact and they did not want to discuss this.
- 45% of the parents said healthcare staff did not talk about the emotional impact but they would have found talking about this helpful.
- Parents in NHS Ayrshire and Arran and NHS Lanarkshire all reported to receive some or full emotional support.
- About 50% of parents in NHS Fife, NHS Forth Valley, NHS Grampian, NHS Greater Glasgow and Clyde, NHS Highland reported to receive some or a lot of emotional support, and around 50% receiving no support.
- In NHS Borders, NHS Lothian and NHS Tayside the large majority of parents reported receiving no emotional support from healthcare staff.
- A number of parents in NHS Greater Glasgow and Clyde, NHS Lanarkshire and NHS Highland reported receiving the CEN website details, CEN patient leaflet and/or CEN DVD. Parents in other health boards reported not knowing about CEN and/or the resources.

Conclusions and actions

26% of parents reported they received a lot of emotional support in 2010, 2011 and 2012; this is much higher than the 7% reported by parents before 2010. Also the number receiving some support increased from 20% to 26%. However, a large percentage of parents (48%) still reported that they did not receive any emotional support and almost all of these parents (45%) reported they would have found talking about the emotional impact helpful.

- The CEN network will have to continue to raise awareness of the importance of discussing the emotional impact of changing from oral feeding to tube feeding at conferences and events.
- CEN will have to contact healthcare professionals in each of the health boards to ask if they use the patient leaflet and DVD, if they require more resources or if there are any reasons why healthcare professionals do not use the resources.
- CEN can offer all health boards training events or presentations to raise awareness of the impact of changing from oral feeding to tube feeding among healthcare professionals
- CEN should prioritise NHS Borders, NHS Lothian and NHS Tayside for training and information events to improve support to families in these areas.