



Surveillance of Cerebral Palsy in Europe:  
best practice in monitoring,  
understanding inequality  
and dissemination of knowledge  
SCPE-NET



## **Gastrostomy tube feeding of children with cerebral palsy: variation across six European countries.**

Dahlseng MO, Andersen GL, DA Graca Andrada M, Arnaud C, Balu R, De la Cruz J, Folha T, Himmelmann K, Horridge K, Júlíusson PB, Páhlman M, Rackauskaite G, Sigurdardottir S, Uldall P, Vik T; Surveillance of Cerebral Palsy in Europe Network.  
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### **Background**

Feeding difficulties and poor growth are common among children with cerebral palsy (CP). The causes contributing to feeding difficulties are many, including difficulties in chewing and swallowing, and gastro-oesophageal reflux (regurgitation of food from the stomach). This leads to poor nutrition, and may in turn lead to impaired growth. Children with these problems may therefore need to have a feeding tube inserted directly into their stomach. This is called a gastrostomy tube, and feeding through this tube is called gastrostomy tube feeding. However, reports from various centers in Europe have shown that the use of gastrostomy tube feeding varies, which may be due to differences in clinical practice (differences in how doctors and other clinicians make decisions about what they do) or in access to this procedure.

### **What was the aim?**

This paper set out to answer the following questions:

1. How many children with CP have feeding difficulties?
2. Are there differences in the use of gastrostomy tube feeding between different European regions?
3. Does differences in gastrostomy tube feeding lead to differences in growth?

### **How was the work carried out?**

Data were collected through the registers participating in the European network for the study of CP (SCPE). However, only six recorded such information. In all 1295 children with CP born between 1999 and 2001 from Norway, Iceland, Denmark, Portugal, Western

Sweden and Northern England were included in the study. The information recorded included if the child has a gastrostomy tube and the age of placement, the child's weight, height and feeding abilities or difficulties.

### **What were the findings?**

Out of all of the registered children, 11 out of every 100 were fed through a gastrostomy tube. The proportion of children with such feeding was highest in Western Sweden with 22 %, while the lowest was in Portugal and Northern England with only 6 % of the children were tube fed. Gastrostomy tube feeding was most common among children with spastic bilateral and dyskinetic CP, and the children with the most severe motor impairments (i.e. children unable to walk). In the latter group the differences between the countries were even more marked (Western Sweden: 67%; Portugal: 12%).

The age of the children when the gastrostomy tube was inserted also differed significantly. Half of the children in Western Sweden had their tube inserted at an age of 16 months while in Northern England, the corresponding age was 70 months. In Norway, half of the children had a tube inserted before they were 19 months and in Denmark before they were 26 months old.

Children with spastic unilateral and ataxic CP subtypes were higher, and weighed more than children with spastic bilateral and dyskinetic subtypes. Among the children with most severe motor impairments we found a difference between the regions for both weight and height. The Portuguese children were smaller than the Nordic children when we compared their growth with the corresponding growth curves of children without CP in the same countries.

We also discovered that feeding abilities are not recorded in the same way, and that a classification system of feeding abilities is needed.

### **What does this tell us?**

There is a great variation in the use of gastrostomy tube feeding in children and young people with CP in Europe, both in the overall use and at what age a tube is inserted. This may in part be due to differences in access to care. More active use of gastrostomy tube feeding may improve growth in weight and height among children with the most severe motor impairments. Feeding difficulties are not reported in a consistent way, and better guidelines for the use of gastrostomy tube feeding are needed.

### **Further work**

Feeding scales are currently being developed, and their validity and reliability need to be examined. These scales should be able to better guide clinicians and parents in the decision of if and when a tube should be inserted. The effect of gastrostomy tube feeding on growth, health and participation needs to be studied in specifically designed studies.

### **Paper**

The full results of this study can be found in *Developmental Medicine Child Neurology*. 2012 Oct;54(10):938-44.

### **Pubmed abstract**

The summary of this study can be found in Pubmed, a database of citations from biomedical journals. <http://www.ncbi.nlm.nih.gov/pubmed/22845753>

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