

Manuscript Nordmark Eva. Friday 21 of Sep 2007

## Slide

1. My name is Eva Nordmark PhD, PT, Senior Lecturer, Division of Physiotherapy, Department of Health Sciences, Lund University, Lund University Hospital in Sweden.

The aim of this presentation “Health promotion of adolescents is to inspire and highlight importance of working together and maximise outcomes for clients with cerebral palsy. I will point out some interesting results and relate them to clinical practice.

The results are based on data from adolescents continuously followed in our prevention program CPUP. Thus I thought it might be meaningful to have a short introduction about our prevention programme.

2. What is CPUP?
3. CPUP started in 1994 as a **secondary** prevention programme in southern Sweden (total 1.3 millions)

Follows a **total** population of children with CP prospectively comprises **all** children living in area and born from 1990, 5% are born abroad.

In 2002 registration of Arm-hand function started.

Since 2005 is CPUP appointed by The National Board of Health and Welfare as a National health care quality register.

In 2007 all parts of Sweden were participating. Half of Norway.

Future directions are to provide this service for the adults and inspire more countries in Scandinavia

4. Why start CPUP?
5. Because we saw children, adolescents and adults with severe secondary impairments. They often have an increased muscle tone, muscle weakness, muscle imbalance, and for this reason are they at an increased risk of developing contractures, skeletal deformities and hip dislocation, windswept, pain, getting fracture and starving.
6. Surgery has been the only treatment alternative but now we have more treatment alternatives and possibilities to use combinations of preventive interventions. However the many treatment options available make it very important that there is a good cooperation between the specialists.  
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7. The aim of the National Quality Register is to: prevent complications to CP especially hip dislocations and severe contractures to improve the cooperation - between different professionals providing habilitation and other health services to people with CP. Improve knowledge - describe the “natural” course of function and development in CP, evaluate different treatment methods, implement evidence based practise.
8. What are we doing?
9. The keywords are: identify and include all children, standardized follow up, early detection, early prevention, standardized measurements
10. The health care programme includes inventories to identify and offer the program to all children with or suspected CP. A continuing standardized follow-up of each child in terms of an assessment form.

The child’s local physiotherapist and occupational therapist fill in the form twice a year until the child is aged six and thereafter once a year.

The assessment form includes the following: the CP-subtype, the gross and fine motor function (GMFCS), the manual ability (MACS), measurements of passive range of motion, clinical findings, use of orthosis and other treatments.

The programme also includes a standardized radiographic follow-up of the children’s hips (Reimers index) and spine.

Yearly education days are arranged for multidisciplinary professionals and the results are presented in a year-book.

Close collaboration with the “Spasticity clinic”, which is multidisciplinary and provide different treatment options.

11. All reports are administered via internet since January 2007.
12. The results are all computerized, and the local health care team receives a report showing the child’s development over time. This example shows range of motion in knee extension, followed since 2002, right and left side, getting decreased range of motion, treated with Botox, casting and intensified physiotherapy.
13. In CPUP we have a signal system “ alarm levels”, which differs according to measured joint and severity of function (GMFCS level I-III or level IV-V).  
 Green = value is normal  
 Yellow= value needs to be checked, follow carefully, change treatment?  
 Red indicates pathological value DO SOMETHING!
14. Now let’s focus on the experiences from the study: Movement related function and activities among adolescents with cerebral palsy.

15. The aim of this study was to survey and describe function, prevalence of physiotherapy, physical activity in school and at leisure time
16. The study group consisted of 137 out of 167 children in an earlier studied population-based cohort. There were 77 (56%) boys and 60 (44%) girls born from 1 Jan 1990 to deck 1993. Living in the Southern most part of Sweden (the counties of Skåne/Blekinge) at the first Jan 1998 and 2006. Mean age of the group was 14 years (12-16) yrs.
17. Distribution of dominating symptoms was Spastic 75%, Ataxic 10%, Dyskinetic 12% and severity of gross motor function according to GMFCS level: I 45%, II 17%, III 14%, IV 12%, V 12%

18. For those who are not familiar with Gross Motor Function Classification System (GMFCS) a short summery:  
It is Classification system for children's severity of gross motor function, related to age consisting of five groups.

Level I represent children with the least and level V the most functional limitations.

At an age of six years children in level I-II are independent walkers, children in level III walkers with device and finally children in level IV-V are none walkers needing extensive device and assistance.

GMFCS are constructed by the Canchild group and the revised and extended GMFCS (now up to 18 yrs of age) will be available at there website.

19. What did we find? The range of motion in hip extension deficits was ranging from 10-46% and especially alarming for the most severe children at risk for hip dislocation!
20. Hip abduction in adolescents. Even worse is the restricted range of motion in the hips, where we can consider that this group needs systematically follow-up and careful observation and multidisciplinary interventions.
21. The tightness in hamstrings is a big problem for the teenagers in all GMFCS levels.
22. Knee extension is a minor problem in GMFC level I-II, however very common in those who are walkers with device and none walkers, GMFCS III-V!
23. Dorsiflexion in the foot – here we see the opposite problem- good range of motion in the most severely disabled. The walkers (without or with device) (GMFCS I-III) have limited range of motion.
24. No standing or standing? That's the question? YES! We put a lot of effort on standing to stretch the muscles daily. It is harder to motivate teenagers and their teachers to implement standing at school. With a standing shell you can stretch hips, knees and feets at the same time as you can train balance and fine motor function. 27% of the children in GMFCS level V were not standing.

25. Most of these teenagers in GMFCS I-III are able to sit in an ordinary chair, however the severely disabled children have a lot of modifications and it is problematic to find variations in sitting.
26. We try to avoid too much sitting and asymmetries to prevent scoliosis.
27. In the group as a whole 1/4 of the teenagers had a scoliosis, 10% of these were reversible, more frequent in the more severely disabled children.
28. The frequency of individual physiotherapy treatment increased with severity of function, 15% GMFCS I less and GMFCS V most. Physiotherapy in water was the most common form of physiotherapy.
29. Only about half of the children in GMFCS level III-IV participated at the school physical education.
30. Swimming and horse riding most common activities for all children GMFCS I and II had largest variation in physical activity at leisure time on level V there was no other activity but horse riding and swimming.
31. The implications of this study are that restricted movement in hip knee and feet among teenagers is common and an important observation. In combination with growth this leads to difficulty to stand, walk and move. Preventing further development of contractures is necessary. Varied body positioning in sitting and standing are important. All children should be provided pleasurable and meaningful physical activities at school as well as at leisure time.
32. CPUP is a new way of working - we have learnt that prevention is a sound and more health related treatment, we have learnt – don't wait ! It can be too late!
33. No child following the prevention program has developed hip dislocation. Before CPUP, 10% of the children developed hip dislocation
34. The number of children with severe contractures has been reduced with 70%. The number of children with windswept deformity has been reduced, as well as the severity of the deformity.
35. The number of children with severe scoliosis has been reduced with 60%.
35. Orthopaedic surgery for contracture or skeletal torsion deformity decreased from 40 to 15% (p=0.0019)
36. CP is a condition that spans a lifetime and need to be early identified and continuously systematically followed-up in a multidisciplinary way even into adulthood. The many treatment options available make it very important that there is a good cooperation between all specialists. A register like CPUP is a good base for this cooperation. Population based studies with longitudinal designs following children from childhood into teens are rare, but needed for a better planning of service and transition into adulthood.

