Eating and Drinking Ability Classification System (EDACS) for people with cerebral palsy: what is it good for?

www.edacs.org

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Overview

- Background
- Content
- Using EDACS
- Other applications
- Next steps
• Cerebral Palsy (CP) is a group of permanent, but not unchanging, disorders of movement and/or posture and of motor function, which are due to a non-progressive interference, lesion, or abnormality of the developing immature brain. (Cans et al. 2009)

• Prevalence 2 children per 1,000 live births (Sellier et al. 2016)
Cerebral Palsy

Affects many areas of function including:

- Sitting, standing, walking
- Speech and language development
- Use of hands
- Senses including vision and hearing
- Eating, drinking and swallowing
Nutrition Team providing clinical care to children and young people with complex physical disability: Paediatrician, Dietitian, Nutrition Nurse Specialist, Speech and Language Therapist
Each member has different:

- Professional training
- World view
- Roles
- Responsibilities
- Interests
- Styles
- Language and jargon
- Frameworks
- Goals
Questions arising from team...

- Is there a way of simplifying the description of someone’s eating and drinking ability?
- What are the key points concerning someone’s eating and drinking ability that all team members need to know?
- Is there a means of classifying eating and drinking ability to show that one child’s ability is more limited than another’s?
• 22% of identified deaths for people with CP resulted from solids or liquids in their lungs or windpipe

• Where difficulty swallowing was mentioned on death certificate (only 3%) cause of death in 60% of these cases was solids or liquids in the lungs or windpipe

Improving Health and Lives Learning Disabilities Observatory (2010)
Wider networks...

Nutrition Team

- Adult Services
- Specialist Surgery: orthopaedic, gastrostomy, ENT etc.
- Specialist NHS services
- Other schools
- Respite care

- Chailey Heritage Care staff
- Chailey Heritage School staff

Acute Hospitals

- Social Services
- Research

- Commissioners
- GPs
- Community NHS services
- Other Chailey Heritage Clinical Services teams
- Parents

Other schools

Specialist NHS services

Research

Commissioners
GPs
Community NHS services
Other Chailey Heritage Clinical Services teams
Parents
Local solution ...

- Adult Services
  - Specialist Surgery: orthopaedic, gastrostomy, ENT etc.
    - Specialist NHS services
  - Other schools

- Acute Hospitals

- Social Services
  - Commissioners
    - GPs
  - Community NHS services
  - Research
    - Other Chailey Heritage Clinical Services teams
    - Parents

- Nutrition Team
  - Chailey Heritage Care staff
  - Chailey Heritage School staff

- Other schools

- Respite care

- Chailey Heritage Care

- Chailey Heritage School

- Other Chailey Heritage CLinical Services teams

- Community NHS services

- Research

- Commissioners
  - GPs

- Social Services

- Acute Hospitals

- Adult Services
  - Specialist Surgery: orthopaedic, gastrostomy, ENT etc.
  - Other schools
But not this ...

Child with cerebral palsy and family

Acute Hospitals

Social Services

Commissioners

GPs

Community NHS services

Other Chailey Heritage Clinical Services teams

Research

Nutrition Team

Chailey Heritage School staff

Chailey Heritage Care staff

Respite care

Other schools

Specialist NHS services

Specialist Surgery: orthopaedic, gastrostomy, ENT etc.

Other Chailey Heritage Clinical Services teams

Commissioners

GPs

Community NHS services

Respite care

Specialist NHS services

Specialist Surgery: orthopaedic, gastrostomy, ENT etc.
Gross Motor Function Classification System GMFCS

Based on concepts of disability and “limitation in performance at the level of the whole person” (Nagi 1965)

NOT:

• parts of body most involved
• neuro-anatomical location of lesion
• impairment in muscle tone, voluntary control of activity

(Palisano et al. Dev Med Child Neuro 1997)
GMFCS - Summary

- **Level I** – walks without limitations
- **Level II** – walks with limitations
- **Level III** – walks using a hand held mobility device
- **Level IV** – self-mobility limitations; may use powered mobility
- **Level V** – transported in a manual wheelchair
Feeding difficulties

Poor feeding is one of the major risk factors for early death and is related to GMFCS level. Limited data exist about the true prevalence of feeding difficulties, with rates often skewed by ascertainment sources and age. Cross sectional studies suggest that problems with sucking (57%), chewing (69%), and swallowing (38%) are common. Children with more severe motor impairment (GMFCS level 4 or 5) have the greatest risk, with 91-99% having clinically important oromotor dysfunction. This can lead to major impairment in feeding ability, lengthy distressing mealtimes, growth disturbance, and malnutrition. Multicentre cross sectional studies estimate that malnutrition affects 50% of children with cerebral palsy and is more common in those at GMFCS levels 3-5. Feeding difficulties can also result in aspiration of food and fluid into the lungs.

Table I: Feeding ability with respect to degree of motor disability, n (%)
• Other functional classification systems for people with CP:
  – Manual Ability (MACS Eliasson et al. 2006)
  – Communication Function (CFCS Hidecker et al. 2011)
  – Viking Speech Scale (Pennington et al. 2013)
• Ordinal scales (I – IV or V)
• Measures of the extent of limitations to function
• Suitable for use in clinical and research contexts
Are you familiar with the Gross Motor Function Classification System (GMFCS)?

1. Yes 41%
2. No 59%
Are you familiar with the Manual Ability Classification System (MACS)?

1. Yes  10%
2. No  90%
Are you familiar with the Eating and Drinking Ability Classification System (EDACS)?

1. Yes  13%
2. No     87%
Question 4

Are any of these Functional Classification Systems in regular use at your place of work?

1. Yes  34%

2. No  66%
Definition and evaluation of content:

1. Construct EDACS draft
2. Nominal Group Process
3. Delphi Survey
4. Reliability Studies

Evaluation of reliability when used by different observers:

Revise Draft
Revise Draft
Participants

• Speech and Language Therapists ... 47%
• Paediatricians ... 14%
• Parents ... 7%
• People with CP ... 7%
• OTs / Physios ... 7%
• Nurses ... 5%
• Dietitians ... 4%
• Other ... 9%
TOTAL n=151
EDACS – Key Features

• Safety - aspiration and choking
• Efficiency - food loss and time taken
• 5 level ordinal scale - describing full range of eating and drinking ability of people with CP
• 3 level ordinal scale – describing assistance required in bringing food and drink to mouth
• Age Range - from 3 years to adulthood
Eating and Drinking Ability Classification System

- Is the individual able to swallow food and drink without risk of aspiration?
  - Yes
  - No
    - Can risks of aspiration be managed to eliminate harm to the individual?
      - Yes
      - No

- Is the individual able to bite and chew on hard lumps of food without choking?
  - Yes
  - No
    - Is the individual able to eat a meal in the same time as peers?
      - Yes
      - No

**Level I**
Eats and drinks safely and efficiently.

**Level II**
Eats and drinks safely but with some limitations to efficiency.

**Level III**
Eats and drinks with some limitations to safety; there may be limitations to efficiency.

**Level IV**
Eats and drinks with significant limitations to safety.

**Level V**
Unable to eat or drink safely – tube feeding may be considered to provide nutrition.
Group work - 15 mins

Use these documents:

• EDACS
• 6 brief case reports

Decide:

• Level which best describes child’s eating + drinking ability
• Best description of assistance required
Case study - Beth

What EDACS level best describes her eating + drinking ability?

1. Level I 0%
2. Level II 87%
3. Level III 11%
4. Level IV 2%
5. Level V 0%
Case study - Beth

What level of assistance do you think Beth needs?

1. Independent 25%
2. Requires Assistance 74%
3. Totally Dependent 2%
Case study - George

What EDACS level best describes his eating + drinking ability?

1. Level I 0%
2. Level II 0%
3. Level III 2%
4. Level IV 65%
5. Level V 33%
Case study - George

What level of assistance do you think George needs?

1. Independent
   0%

2. Requires Assistance
   50%

3. Totally Dependent
   50%
**Case study - Jane**

What EDACS level best describes her eating + drinking ability?

1. Level I  0%
2. Level II  0%
3. Level III 6%
4. Level IV 59%
5. Level V 35%
Case study - Jane

What level of assistance do you think Jane needs?

1. Independent  0%
2. Requires Assistance  8%
3. Totally Dependent  92%
Case study - Josie

What EDACS level best describes her eating + drinking ability?

1. Level I  
   - 17%
2. Level II  
   - 17%
3. Level III  
   - 67%
4. Level IV  
   - 0%
5. Level V  
   - 0%
Case study - Marco

What EDACS level best describes his eating + drinking ability?

1. Level I 0%
2. Level II 18%
3. Level III 45%
4. Level IV 36%
5. Level V 0%
Case study - Simon

What EDACS level best describes his eating + drinking ability?

1. Level I  22%
2. Level II  43%
3. Level III  30%
4. Level IV  4%
5. Level V  0%
Comments or questions?
Paired ratings for 100 children with CP (4 - 22 yrs)

- **SaLT1 vs. SaLT2 - EDACS**
  - Absolute agreement: 78%
  - Chance corrected agreement (kappa): 0.72
  - ICC (consistency single measures): 0.93 (0.90 – 0.95)

- **SaLT1 vs. SaLT2 level of assistance**
  - Absolute agreement: 87%
  - Chance corrected agreement (kappa): 0.80
  - ICC (consistency single measure): 0.86 (0.76 – 0.92)
User feedback

• Easy to use
• Parents can recognise their children in descriptions
• Parents surprised their children had similar difficulties to other children with CP
• Helped parents think more about eating and drinking
• Differences between SaLTS and parents consistent
Paired ratings for 48 children with CP (4 – 17 yrs)

• SaLT1 vs. parents - EDACS
  – Absolute agreement: 58%
  – Chance corrected agreement (kappa): 0.45
  – ICC (consistency single measures): 0.86 (0.76-0.92)

• SaLT1 vs. parents - level of assistance
  – Absolute agreement: 79%
  – Chance corrected agreement (kappa): 0.64
  – ICC (consistency single measures): 0.77 (0.62-0.87)
Clinical questions

• Can we predict how a child’s eating and drinking ability will change over time?

• What are the links between a child’s ability to eat and drink and rates of growth?

• What are the links between a child’s ability to eat and drink and other abilities such as gross motor function, speech, hand function, and communication function?
Discuss from your experience of children with CP:

- Will children’s EDACS levels stay the same over time?
- What are the links between weight/age centiles + EDACS level for children with CP?
- What are the links between children’s gross motor function and eating/drinking ability?
What changes in EDACS levels would you expect over time for most children with cerebral palsy?

1. Stay the same  | 4%
2. Change by up to 1 level | 33%
3. Change by up to 2 levels | 47%
4. Change by up to 3 levels | 7%
5. Change by up to 4 levels | 4%
6. Unsure | 6%
What do you think the links are between weight-for-age centile and EDACS levels III – IV for children with CP (no tube-feeding)?

1. Normal spread across centiles 0%
2. EDACS levels III – IV <0.4th – 25th centiles 81%
3. EDACS levels III – IV 25th – 75th centiles 14%
4. EDACS levels III – IV 75th - >99th centiles 0%
5. Unsure 6%
Question 17

What are the links between weight-for-age centile and EDACS levels I – II for children with CP (no tube-feeding)?

1. normal spread across centiles
   - 16%

2. EDACS levels I – II <0.4th – 25th centiles
   - 25%

3. EDACS levels I – II 25th – 75th centiles
   - 52%

4. EDACS levels I – II 75th - >99th centiles
   - 3%

5. Unsure
   - 4%
What is the link between children’s gross motor ability (GMFCS Levels I - V) and eating + drinking ability (EDACS levels I – V)?

1. no link  
   - 2%

2. EDACS levels sometimes same as GMFCS levels  
   - 33%

3. EDACS levels mostly same as GMFCS levels  
   - 59%

4. EDACS levels always same as GMFCS levels  
   - 0%

5. Unsure  
   - 5%
Retrospective Case Note Review

• Case notes and online records examined for 100 children with CP e.g. mealtime guidance, multi-professional reports

• Rater 1 recorded children’s functional abilities using functional classification systems at Time Point 1

• Eating/drinking ability and gross motor function recorded with GMFCS and EDACS at 3 more time points > 2 years between each

• Rater 2 assigned EDACS levels for 25 children at all time points

• Recorded weights / age at 4 Time Points where available
Results

• **Stability of EDACS over time:**
  
  ICC 0.97 (95% CI 0.96-0.98)
  
  EDACS levels remained stable although children changed how they used underlying abilities

• **EDACS changes over time:**
  
  – 15/100 changed by 1 level
  – 3/15 improved function from Level IV to Level III
  – 10/15 lost function by 1 level between 12 and 19yrs
  – 11/12 who lost function had orthopaedic issues and/or seizures (7 children GMFCS V; 4 children GMFCS IV)
Number of children within each weight-for-age centile group at Time Point 1, by EDACS level

Weight for age centiles from typical growth charts
Children’s eating and drinking ability (EDACS) and gross motor function (GMFCS)

Significant moderate positive correlation between EDACS and GMFCS ($\text{Kendall’s } \tau^b=0.6 \ p<0.001$)

**Results**

Significant moderate positive correlation between EDACS and GMFCS ($\text{Kendall’s } \tau^b=0.6 \ p<0.001$)
Emma’s Story

- **Gross Motor Function:** I Walks without limitations
- **Manual Ability:** I Handles objects easily and successfully
- **Communication Function:** III Effective sender & receiver with familiar partners; changing to II effective sender and receiver information with familiar and unfamiliar partners but may need extra time
- **EDACS:** Consider EDACS level over time
Group work – 10 mins

Use these documents:

- EDACS
- Martha’s story

Decide:

- What EDACS level best describes Martha’s eating + drinking?
- What are your concerns?
- What are you going to do?
What EDACS level best describes Martha’s eating + drinking?

1. EDACS Level I – Totally Dependent
   0%
2. EDACS Level II – Totally Dependent
   0%
3. EDACS Level III – Totally Dependent
   5%
4. EDACS Level IV – Totally Dependent
   59%
5. EDACS Level V – Totally Dependent
   36%
What are your concerns?

1. Impact on growth and health of limited oral intake: 64%
2. Safety: 18%
3. Prolonged mealtimes (i.e. efficiency): 10%
4. Coercion to eat + drink / communication with Martha: 3%
5. Seating – affected by posture + muscle tone: 0%
6. Parents’ views: 3%
7. Other concerns: 3%
Question 21

What are you going to do?

1. nothing – not your responsibility
   0%

2. work with other MDT members to address issues
   44%

3. reduce mealtime length in school
   0%

4. ensure staff respond to Martha’s communication
   2%

5. meet with parents to discuss gastrostomy
   11%

6. meet with parents to discuss concerns + make plan
   42%
Comments or questions?
In summary

- **EDACS** - valid and reliable system
- Classifies eating and drinking performance of people with CP from age 3 years
- Useful in clinical and research contexts
- Free to download from [www.edacs.org](http://www.edacs.org)
- Published by Dev Med Child Neurology: Sellers et al. March 2014; Sellers et al. April 2014
In summary

- EDACS appearing in clinical records across UK
- EDACS recognised as one of Functional Classification Systems for CP
- 23 translation requests received (including most European languages, Arabic, Chinese, Hebrew, Japanese and Korean)
- Adopted by international CP surveillance registers and international research groups
Any questions or comments?

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