



**The National Rehabilitation  
Center for Neuromuscular Diseases**

# **”Egen Klassifikation” Scale II Manual EK2**

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## Introduction

The EK scale was developed as an instrument to measure changes, even small ones, in physical function over time in wheelchair users with spinal muscular atrophy (SMA) and Duchenne muscular dystrophy (DMD). The name EK stands for Egen Klassifikation meaning “self-classification” as it captures a person's experience of everyday ability.

The scale is a composite scale consisting of 17 items; each item is scored using four categories from 0 to 3 based on a face-to-face interview with the person about how the individual items are normally performed. If possible, the person is asked to demonstrate the performance. The EK-sum score is calculated as the sum of all items. Maximum score (51) represents lowest function, and minimum score (0) represents highest function. Originally 10 items it was extended to 17 items hence, EK2 scale.

The scale can be used and is useful for other NMD who are no longer walking but is only validated for non-ambulant persons with SMA and DMD. The answer to each item, not just the score, helps guide appropriate management.

## Practical implementation

- The examination is conducted as a conversation in which the person and carer, if any, are interviewed by the evaluator about how the individual items (EK 1-17) are normally performed followed, if possible, by a demonstration of how they are performed.
- The aim is to gather as much accurate information as possible, so if the person does not know the answer to a question, it is important to obtain information from those who are with / assist the person on a regular basis.
- The items on the scale are scored according to the best an individual has done in the last two weeks especially if there is variation between good and bad days. If a score falls between two categories choose the score that represent the highest functional ability (the lower score / better function).
- This ‘best functioning’ applies even though most items on the scale say “ability to” perform the activity.
- The items -EK7 “ability to turn in bed” (categories 2 and 3), and - EK10 “respiratory insufficiency” are, however, *purely interviews*.
- **Exceptions** to this are the items - EK4 “ability to balance in the wheelchair” and EK5 - “ability to move the arms”. Here, the individual is examined in order to evaluate **what they actually are capable of**, not the best they have done in the last two weeks.
- The examination is conducted in a normal wheelchair with all its special equipment, with the seat adjusted as horizontally as possible (not tilted).
- If the individual uses a back or neck brace to support position, they keep it on.
- An electric harness, if any, must only be used as a stationary harness, not to change position.
- All usual positioning devices or positioned are maintained but don't use wheelchair functions to improve ability such as tilt.

## Acknowledgements

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We would like to thank the young man, Frederik Borggaard, who helped illustrate the EK2 items and dedicate this manual to his memory.

## Scoring the individual items (EK 1-17)

### Uncertainties in scoring

If a score falls between two categories, the one that represents the **highest functional ability** (lowest score) should be chosen.

### EK 1: ABILITY TO USE WHEELCHAIR

| Questions to individual | <p>How do you usually get around indoors and outdoors?<br/>Do you ever use a manual wheelchair?</p> <p style="text-align: center;">↓</p> <p>Show me how far you can push it or explain to me how you do this</p> <p style="text-align: center;">↓</p> <p>To clarify between a score of 2 or 3 ask: <i>Are there situations where it can be difficult for you to steer the wheelchair, for example, when it's cold?</i></p> |  |
|-------------------------|--|--|
| Score                   | Scoring Options  | Additional Information   |
| 0                       | Able to use a manual wheelchair on flat ground, for 10 metres or more  | Can ask to perform   |
| 1                       | Able to use a manual wheelchair on flat ground but for less than 10 metres   | Can ask to perform   |
| 2                       | Unable to use manual wheelchair, requires power wheelchair   | The individual steers the power wheelchair without difficulty  |
| 3                       | Uses power wheelchair, but occasionally has difficulty steering  | The individual reports that he cannot steer the chair if, for example, his fingers are cold, he is driving uphill, is wearing a lot of clothes, etc. |
|                         |   |  |

Score 1 – Uses a power wheelchair and reports no difficulty in steering

## EK 2: ABILITY TO TRANSFER FROM WHEELCHAIR

| <b>Questions to individual</b> | <p>How do you transfer from the wheelchair to a bed?</p> <p style="text-align: center;">↓</p> <p>Show me or explain to me how you do this</p> <p style="text-align: center;">↓</p> <p>Category 2 or 3 can be explained or demonstrated by the test person and helper, if any.</p> |  |
|--------------------------------|---|--|
| Score                          | Scoring Options   | Additional Information   |
| 0                              | Able to transfer from wheelchair without help   |  |
| 1                              | Able to transfer <u>independently</u> from wheelchair, with use of aid  | Aid could be a sliding board   |
| 2                              | Needs assistance to transfer with or without additional aids ( <u>hoist without needing head supported</u> , easy glide)  | Hoist <u>without needing head supported</u> or may also be a standing transfer, the person's knee against the helper's knee.                               |
| 3                              | Needs to be lifted with <u>support of head</u> when transferring from wheelchair  | Uses a lift sling that reaches all the way up around the neck in order to support the head or as described when undertaking a sitting-to-sitting transfer. |

## EK 3: ABILITY TO STAND

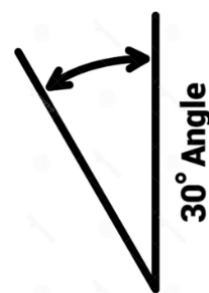
| Questions to individual | <p>Do you sometimes stand? How do you do this?</p> <p style="text-align: center;">↓</p> <p>Show me or explain to me how you do this</p> <p style="text-align: center;">↓</p> <p>Category 3 may or may not include contractures</p> |   |
|-------------------------|--|---|
| Score                   | Scoring Options  | Additional Information  |
| 0                       | Able to stand briefly either independently or using arms for support or with support of a person   | A score of 0 will include those able to stand independently even briefly with or without support – the two boxes here allow us to capture those who can stand for short periods without altering the original scoring procedure |
| 0                       | Able to stand with <u>knees</u> supported, as when using braces  |   |
| 1                       | Able to stand with <u>knees and hips</u> supported, as when using standing aids  | Standing aid is a rollator, frame or table which gives knee and hip support   |
| 2                       | Able to stand with <u>full body support (trunk-hips-knees)</u>   | This would include such things a tilt table, standing frame with trunk support or in a wheelchair with standing function.   |
| 3                       | Unable to be stood   |   |



*Score 0 – Able to stand when holding onto chair – no braces or additional support needed*

## EK 4: ABILITY TO BALANCE IN THE WHEELCHAIR

| Questions to individual | <p>Can you bend forward and to the sides and return to upright position?</p> <p style="text-align: center;">↓</p> <p style="text-align: center;">Show me how</p> <p><b>NOTES</b></p> <ul style="list-style-type: none"> <li>The wheelchair seat must be as horizontal as possible and must not be tilted during the testing of this item.</li> <li>Any side supports must be removed if possible.</li> <li>An electric harness, if any, must only be used as a stationary harness, not to change position.</li> <li>A brace, if any, is kept on</li> <li><u>The movement has to be in the trunk</u>, and not just shoulder girdle and head. Compensatory movements are allowed.</li> </ul> |  |
|-------------------------|--|--|
| Score                   | Scoring Options  | Additional Information   |
| 0                       | Able to push himself upright from complete forward flexion by pushing up with hands  | The upper body must reach all the way down and rest on the thighs, both hands must touch the foot support / foot and the person must rise unaided by another person or additional furniture from this position. Using the hands to support and propel the upper body is allowed. |
| 1                       | Able to move the upper part of the body $> 30^\circ$ <u>in at least one direction</u> from the upright position, but cannot push himself upright as above  | Can bend the upper body $> 30^\circ$ in at least one direction: either forward or to one side and return to upright position.  |
| 2                       | Able to move the upper part of the body $< 30^\circ$ from one side and back, <u>in at least one direction</u>  | Can bend the upper body to $< 30^\circ$ in at least one direction: either forward or to one side and return to upright position.   |
| 3                       | Unable to change position of the upper part of the body, cannot sit without total support of the trunk and head  | Is unable to move away from the back of the chair. Individuals who sit in a permanent forward leaning position with support to the front of the body also score 3.   |



Score 2- As he is able to lean to one side more than  $30^\circ$

## EK 5: ABILITY TO MOVE THE ARMS

| Questions to individual | <p>How high can you lift your arms and hands? Can you move your fingers, hands or arms? Can you raise one or both hands to your mouth? How much can you move them?</p> <p style="text-align: center;">↓</p> <p style="text-align: center;">Show me how you do this</p> <p><b>NOTE :</b> Be aware that movements are related to shoulder joint, elbow joint and wrist and should start from the person's lap.</p> |  |
|-------------------------|--|--|
| Score                   | Scoring Options  | Additional Information   |
| 0                       | Able to raise at least one arm <u>above the head</u><br>Compensatory movements are allowed, but head must not be bent to reduce the distance.  | Can raise at least one arm <u>above the head</u> .<br>Compensatory movements are allowed, but the head cannot be bent / flexed to reduce the distance. |
| 1                       | Unable to lift arms above the head, but able to raise the forearms against gravity, <u>hand to mouth</u> with or without elbow support   | Can raise at least one forearm up to the mouth. Compensatory movements and elbow support are allowed   |
| 2                       | Unable to lift the forearms against gravity, but able to use the hands against gravity when the forearm is supported   | Can raise at least one hand against gravity. Forearm support on table or table edge is allowed   |
| 3                       | Unable to move the hands against gravity but able to use the fingers   | For example, drive a powered wheelchair if hand is placed or use a touch screen  |

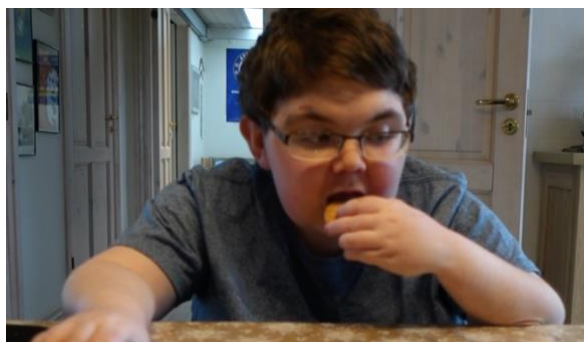


*Score 1- Able to raise forearms and lift hand to mouth with elbow supported.*

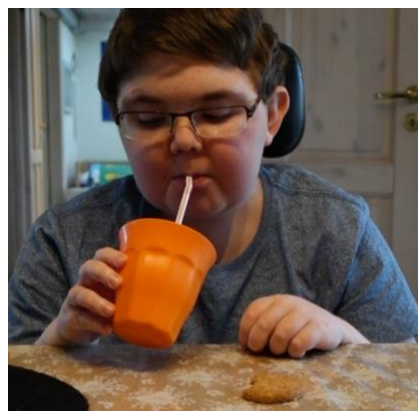


## EK 6: ABILITY TO USE HANDS AND ARMS FOR EATING

| Questions to individual | <p>Can you describe how you eat?<br/>Do you need your elbow on the table when eating?<br/>If so, do you use your other hand to help?</p> <p style="text-align: center;">↓</p> <p>Show me or explain to me how you do this</p> |  |
|-------------------------|---|--|
| Score                   | Scoring Options   | Additional Information   |
| 0                       | Able to eat and drink <u>without elbow support</u>  | Can raise cup or glass to mouth and eat using knife, fork or spoon if relevant <b>without</b> the need of elbow support  |
| 1                       | Eats or drinks <u>with elbow support</u>  | Needs elbow support (from armrest or table) to eat and/or drink  |
| 2                       | Eats and drinks <u>with elbow support and reinforcement of the opposite hand</u> +or – aids such as straw   | As described and/or with compensatory movements e.g.by supporting forearm over the edge of the table<br><br>An alternative option such as a high table or raised desktop is allowed for this score |
| 3                       | Has to be fed   | This would include a mobile arm/ mechanical arm / a “neateater” and or an assistant  |



Score 2 – the table is elevated and forearm (not just elbow) is supported on table edge




Score 2 - High table, forearm support, straw in cup

## EK 7: ABILITY TO TURN IN BED

| <b>Questions to individual</b> | <p>How do you turn in bed during the night?</p> <p style="text-align: center;">↓</p> <p>Explain to me how you do this</p> <p><b>NOTE:</b> If the individual is able to turn himself partially or totally the number of turns is not important. <u>If in doubt, ask the caregiver, because the person may not know the number of turns.</u></p> |   |
|--------------------------------|--|---|
| Score                          | Scoring Options  | Additional Information  |
| 0                              | Able to turn in bed with bedclothes. Number of turns is not important  | Turns himself from back to side to both sides; number of turns is not important   |
| 1                              | Needs some help to turn in bed or can turn in some directions  | <p>Able to turn partially in bed or can turn in one direction but not back again. May need help</p> <p>Help is defined as: Needs rail to pull on, someone else needs to position legs or adjust covers</p>                      |
| 2                              | Unable to turn in bed. Must be turned 0 - 3 times during the night   | The most common number of turns is 0-3 times. <u>This category included those that can't turn and don't need to be turned during the night.</u> Remember it is during the prior two weeks that you are assessing.               |
| 3                              | Unable to turn himself in bed. Must be turned $\geq 4$ times during the night  | <p>The most common number of turns is 4 or more times.</p> <p>Sometimes the aide's report is preferable. If there is a large deviance, the question is narrowed down to an approximate average during the previous 14 days.</p> |



## EK 8: ABILITY TO COUGH

| Questions to individual | <p>How do you cough <u>when you have to</u>?</p> <p style="text-align: center;"></p> <p>May I hear how it sounds?</p> <p><b>NOTE:</b> If the individual reports that he never coughs, evaluate by asking them to cough. Listen to cough sound and throat clearing.<br/>It is the person's ability to cough by himself that is evaluated.</p> |   |
|-------------------------|---|---|
| Score                   | Scoring Options   | Additional Information  |
| 0                       | Able to cough effectively   | Always coughs without help, powerful coughing sound.  |
| 1                       | Weak cough but able to clear throat. <u>Sometimes</u> needs help with coughing.   | <p>Usually manages without help.</p> <p>In case of infection, might need help with coughing (air-stacking / breath-stacking device, CPAP, manual reinforcement.)</p> <p>Manual reinforcement means a carer's help not equipment</p> |
| 2                       | Ineffective cough and unable to clear throat independently. <u>Always needs help with coughing and sometimes needs device.</u>  | <p>Always needs help with coughing.</p> <p>Help could be air-stacking / breath-stacking device, CPAP, the need to adopt certain position every time. They may <u>sometimes</u> need a cough assist device</p>                       |
| 3                       | Unable to cough, needs suction, hyperventilation techniques or cough assist to keep airways clear   | <p>Unable to cough or so weak that mechanical assistance is required. Needs suction and/or hyperventilation techniques or IPPB in order to keep airways clear.</p> <p>Includes cough assist machine</p>                             |

## EK 9: ABILITY TO SPEAK

|                                |   |  |
|--------------------------------|---|--|
| <b>Questions to individual</b> | <p>Can you speak so powerfully that what you say can be understood if you sit at the back of a large room?</p> <p style="text-align: center;">↓</p> <p>Would you be willing to show me?</p> <p style="text-align: center;"><b>NOTES:</b></p> <ul style="list-style-type: none"> <li>• The voice is evaluated regardless of whether the individual uses assisted ventilation.</li> <li>• Sometimes they are not aware of their quiet voice. In this instance score what you hear not what they say.</li> </ul> |  |
| <b>Score</b>                   | <b>Scoring Options</b>  | <b>Additional Information</b>  |
| 0                              | Powerful speech. Able to sing and speak loudly  | Is able to maintain powerful speech for a long period of time                                |
| 1                              | Speaks normally, but cannot raise his voice   | Speaks with a soft voice (may be able to raise his voice, but not for long periods of time). |
| 2                              | Speaks with quiet voice and needs a breath after 3 to 5 words   | Speaks with a quiet voice and/or needs a breath after just a few words.                      |
| 3                              | Speech is difficult to understand except to close relatives   |  |

## EK 10: RESPIRATORY INSUFFICIENCY – IMPACT ON PHYSICAL WELL-BEING

| Questions to individual | <p>Do you sleep well at night? Do you have a headache in the morning?</p> <p style="text-align: center;"></p> <p>Do you have trouble waking up in the morning? How are your moods?</p> <p style="text-align: center;"></p> <p>Have you lost weight? How is your appetite? When you rest are you restless?</p> <p style="text-align: center;">Are you afraid to be alone at home?</p> <p><b>NOTE:</b> This item is relates to respiratory insufficiency, not to motor difficulties or gastrointestinal difficulties.</p> |   |
|-------------------------|---|---|
| Score                   | Scoring Options   | Additional Information  |
| 0                       | No complaints, feels good   |   |
| 1                       | Poor quality of rest means they tire quickly and need to change position frequently.  | Hypoventilation means they need to change position in wheelchair quite often (they use the electrical functions - tilt and backrest to change position frequently). Restless at rest.   |
| 2                       | Has morning headaches, loss of weight, loss of appetite, scared of falling asleep at night, sleeps badly  | Hypoventilation leads to morning headaches, loss of weight, loss of appetite and associated poor sleep. (Not due to late bedtimes)  |
| 3                       | Experience additional symptoms: change of mood, stomach ache, palpitations, perspiring.   | Symptoms from category 2 and experience additional symptoms to score 2: Palpitations and perspiring. These symptoms are rarely seen now as individuals are usually started on ventilation to ameliorate them. However, you should be aware of them. |

## EK 11: DAYTIME FATIGUE

| Questions to individual | Do you have to organise your day or take a rest to avoid getting too tired?        |   |
|-------------------------|--|---|
| Score                   | Scoring Options  | Additional Information  |
| 0                       | Doesn't get tired during day<br>OR<br>Tired, but does not limit activities         | Doesn't get tired or need to adapt structure of day. Does not take nap / rest   |
| 1                       | Need to limit activities to avoid getting too tired                                | Limits activity to avoid tiredness. E.g. avoids daytime activity if going out at night or vice versa.                       |
| 2                       | Need to limit my activity <b>and</b> have a rest period to avoid getting too tired | If needs rest during the day scores 2. Can include using backrest as flat as possible to rest not just lying down on a bed. |
| 3                       | Get tired during day even if I rest and limit activity                             |   |

## EK 12: HEAD CONTROL

| Questions to individual | How much head support do you need in your wheelchair? The wheelchair's seat should be as horizontal as possible.                                 |   |
|-------------------------|--|---|
| Score                   | Scoring Options  | Additional Information  |
| 0                       | Does not need head support   | Does not need head support. Full control of head even going up or down slopes (standard access ramp), does not need support of neck/head to prevent head falling backwards or forwards. (May have a head support on chair as supplied but <u>never needs it</u> ) |
| 1                       | Needs head support when going up/ down a slope (15° standard ramp), but <u>does not need head support</u> when driving wheelchair on flat ground | Needs head support of some nature (head rest, hand of carer) when going up and down slopes (standard access ramp)   |
| 2                       | Needs head support when driving wheelchair indoors and outdoors, but can sit without head support when the wheelchair isn't moving               | Needs head support when driving wheelchair indoors or outdoors  |
| 3                       | Always needs head support when in wheelchair even when stationary  | Always needs head support   |

## EK 13: ABILITY TO CONTROL JOYSTICK

| Questions to individual | <p>What kind of joystick do you use to control your chair?</p> <p style="text-align: center;">↓</p> <p>Show me how you control your wheelchair</p> <p>Has it been adapted in any way to suit your needs?</p> |   |
|-------------------------|--|---|
| Score                   | Scoring Options  | Additional Information  |
| 0                       | Uses a standard joystick <u>without special adaptation</u>   | Standard joystick means as issued by wheelchair suppliers positioned on either the right or the left of the chair.  |
| 1                       | Uses an adapted joystick or has adjusted wheelchair in order to use joystick   | Score 1 if any adaptation has been made to either the joystick or to its position on the chair. (increasing length of joystick, altering range of motion, "golf ball", moving joystick's position)  |
| 2                       | <u>Uses other techniques for steering</u> than joystick such as blowing sucking systems or scanned driving   | Scanned driving needs minimal strength. A score of 2 is also meant for new techniques and for persons who can partly operate their w/c but need assistance for special manoeuvres such as turning the chair or driving on uneven surfaces or in cold weather. |
| 3                       | Unable to operate wheelchair. Needs another person to operate it   | If there are carer controls in situ due to cognitive issues rather than physical abilities, make a note of this   |



Score 1 – Standard joystick with no modifications



**EK 14: FOOD TEXTURES**

| <b>Questions to individual</b> | Do you have to modify your food in any way in order to eat it? |  |
|--------------------------------|--|--|
| <b>Score</b>                   | <b>Scoring Options</b>   | <b>Additional Information</b>  |
| 0                              | Eats all textures of food                                      | Eats all textures of food without any modification   |
| 1                              | Eats cut up / chunky food or avoids hard/chewy foods           | Eats cut up or small pieces of food or avoids hard/chewy foods, e.g. pizza crusts, roast potatoes, chewy meat          |
| 2                              | Eats minced/ pureed food with supplementation as required      | Eats minced / pureed food  |
| 3                              | Main intake consists of being tube fed                         | Minimal oral intake. They may or may not be tube fed to supplement nutrition but this question is just about textures. |

## EK 15: EATING A MEAL

| Questions to individual | How long does it take to complete a whole meal?  |   |
|-------------------------|--|---|
|                         | <b>NOTE:</b> This will vary from culture to culture. Use the time a normal meal takes within the family.                       |   |
| Score                   | Scoring Options  | Additional Information  |
| 0                       | Able to consume a whole meal in the same time as others sharing the meal   | Able to consume a whole meal in the same time as others sharing the meal  |
| 1                       | Able to consume a whole meal in the same time as others only with encouragement or needs some additional time (approx 10 min)  | Able to consume a whole meal in the same time as others only with encouragement or needs some additional time (approx. 10 minutes).   |
| 2                       | Able to consume a whole meal but requires substantially more time compared to others eating the same meal (15 m or more extra) | Able to consume a whole meal but requires more than 15 minutes extra compared to others eating the same meal or reduces portion size. |
| 3                       | Unable to consume a whole meal   | Unable to consume a whole meal even with additional time, reduced portion size or assistance  |

**EK 16: SWALLOWING**

| Questions to individual | Do you ever have any problems swallowing?  |  |
|-------------------------|--|--|
|                         | <b>NOTE:</b> This includes evaluating if the food is stuck in the throat / pharynx, not just if it has entered the airways |  |
| Score                   | Scoring Options  | Additional Information   |
| 0                       | Never has problems when swallowing and never chokes on food/drink,   | Doesn't choke or have problems swallowing when eating and drinking   |
| 1                       | May experience occasional (less than once a month) problems swallowing certain types of food or occasionally chokes        | Occasionally has a problem swallowing or choking (less than once per a month)  |
| 2                       | Has regular trouble swallowing food/drink or chokes on food/drink (more than once a month)                                 | Has regular trouble swallowing or choking (more than once a month) or needs to sit/lie in a special position, or to turn head (rotate the cervical column) to control swallowing.                              |
| 3                       | Has trouble swallowing saliva or secretions  | Has trouble swallowing saliva or secretions. Comment on how frequently this is a problem and perhaps why. Is it associated with coming off night-time ventilation, having a tracheostomy or a chest infection? |

## EK 17: HAND FUNCTION

| Questions to individual | <p>Can you do the following items using your hands?</p> <p style="text-align: center;">↓</p> <p>Open an unopened bottle of water or fizzy water?</p> <p style="text-align: center;">↓</p> <p>Can you write two lines of text / words?</p> <p style="text-align: center;">↓</p> <p>Can you sign your name or use a remote device or mobile phone?</p> |  |
|-------------------------|--|--|
| Score                   | Scoring Options  | Additional Information   |
| 0                       | Can unscrew the lid of a water or fizzy drink bottle and break the seal  | If the seal is already broken they cannot score 0.   |
| 1                       | Can unscrew the lid of a water bottle, when the seal has been broken   |  |
| 1                       | Can write two lines <b>or</b> use computer keyboard  | Can write two lines of text independently. OK to use the other hand to move paper. Or can use a keyboard with one or two hands (more than just one or two keys). |
| 2                       | Can write signature <b>or</b> send text or use remote control  | Can write signature or name or can send a text message on a mobile phone or use a remote-control device  |
| 3                       | Cannot use hands   |  |



Score 0, if he can unscrew a bottle



Score 1 – He can write at least two lines on a piece of paper