



Clinical Tool

SMA LIFE

Clinical Tool for the Assessment and Monitoring
of Adolescent and Adult Patients
with SPINAL MUSCULAR ATROPHY (SMA)

QUESTIONNAIRE AND MANUAL FOR THE USE OF THE CLINICAL TOOL FOR THE ASSESSMENT AND MONITORING OF ADOLESCENT AND ADULT PATIENTS WITH SPINAL MUSCULAR ATROPHY (SMA)



MANUAL FOR THE USE OF THE CLINICAL TOOL FOR THE ASSESSMENT AND MONITORING OF ADOLESCENT AND ADULT PATIENTS WITH SPINAL MUSCULAR ATROPHY (SMA)

Before starting the questionnaire, please note that:

- The evaluator must be a clinician (preferably a physician) experienced in assessing patients with SMA.
- **All questions refer to the current situation of the patient, taking the past two weeks as a reference.** For some questions that do not involve daily activities, it is allowed to go further back in time, but it is important to clarify why the patient is not performing the activity. If the activity has not been performed because it is very difficult and the patient avoids doing it, it should be scored as 0. If the activity has not been performed because there was no opportunity in the past two weeks, it should be scored according to the expected level of performance or based on the last time it was performed (as long as it was within the last three months). For example, if the patient states that they can climb a flight of stairs with difficulty but has not done so in the last three months, it is highly likely that they are avoiding it by all possible means, and in that case, it should be scored as 0.
- **When scoring each question, the patient will be asked to respond with one of three options:**
 - **Performs the task with ease or at a speed equivalent to that of a person without SMA of a similar age.** For adults, a caregiver or partner may be used as a point of comparison. For children and adolescents, a sibling or schoolmate may serve this purpose. **If the task is performed, in the opinion of the evaluator and the patient, as effectively or as quickly as a person without SMA, even if the method differs, the maximum score of 2 should be assigned.**
 - **Performs the task with greater difficulty:** This score applies to activities performed with less efficiency or more slowly than others, or for which some form of external assistance (orthoses, cane, handrails, handles, etc.) is required, **but without needing help from another person: 1.**
 - **Requires assistance from another person: 0.**
- **The scoring should reflect what the patient does in their daily life, not what they can or could do.** The role of the evaluator is to assist the patient in determining which score best corresponds to their functional level. Generally, the score will be based on the response of the patient unless it directly contradicts what the evaluator observes or expects. In such cases, the evaluator should point this out to the patient and ask for clarification on how the task is performed, then score accordingly. If there is uncertainty, the input of a family member or caregiver may also be sought for that question. For certain tasks, the patient may be asked to perform the activity in front of the evaluator to ensure an accurate assessment. If no agreement is reached, the evaluator will choose the score they deem most appropriate, considering their physical evaluation as well as the responses from the patient and caregiver.
- **For certain tasks, the patient may indicate that they sometimes perform the task alone and other times (e.g., when in a hurry) with help from others.** In this case, it is important to ask what is most common or which parts of the task are performed by each party. Generally, if the task is most commonly performed with assistance, or if the majority of the task is performed with help, it should be scored as requiring assistance (i.e., 0), even if the patient is theoretically capable of performing it alone.
- **In the case of temporary disabilities (e.g., fractures), the score should reflect the current level of function of the patient, not the level they imagine they would have without the temporary condition.**
- In case of doubts, **when the questionnaire is repeated after some time, it may be helpful to have a copy of the previous responses. For items where differences in scoring are noted, the patient can be specifically asked if they have noticed any changes in performing the task** compared to the previous visit.

HOW TO EVALUATE THE DIFFERENT ITEMS?

BULBAR FUNCTION

• Does the patient have clinical signs of bulbar disease?

It includes atrophy or weakness in the tongue, facial weakness, or dysarthria attributable to SMA and not to other causes (e.g., dental problems, idiopathic peripheral facial paralysis, etc.). Fasciculations/isolated myokymia in the tongue should be interpreted with caution, as they are often misinterpreted due to the difficulty in achieving complete rest in the tongue. However, if the expert has no doubts about their presence, they are also considered as a clinical sign.

• To what extent can the patient perform the following activities of daily living?

• Can the patient make themselves understood when speaking to an acquaintance/a stranger/on the phone/in a noisy room?

- *Incapable of doing it without help:* They cannot make themselves understood and need alternative forms of communication, etc.
- *Can do it with difficulty:* They struggle, get tired, need to repeat what they say, sometimes are not understood, need to use gestures, but ultimately manage to be understood.
- *Can do it without difficulty:* They can perform the task in the same way as anyone else.

• Can the patient talk for hours?

- *Incapable of doing it without help:* They cannot maintain long conversations.
- *Can do it with difficulty:* They struggle, get tired, need to rest occasionally, sometimes are not understood, etc.
- *Can do it without difficulty:* They can perform the task in the same way as anyone else.

• Can the patient drink liquids without choking or coughing?

- *Incapable of doing it without help:* They frequently choke or cough when drinking, even with adaptations, or they rely on a PEG tube for nutrition and hydration.
- *Can do it with difficulty:* They occasionally choke or cough, use thickeners, adapted cups, etc.
- *Can do it without difficulty:* They do not choke or cough more than usual (just like any other person).

• How long does it take the patient to complete a meal?

- *Same as the rest of the people (about 30 min).*
- *Up to 15 minutes more than the rest (about 45 min).*
- *More than 15 minutes more than the rest (more than 45 min).*

• Does the patient experience excess saliva in the mouth?

- *Never.*
- *Occasionally:* E.g., when sleeping or during meals.
- *Continually:* Saliva drips or they need to clean themselves with a handkerchief multiple times a day.

• Does the patient need nutritional supplements (nutritional shakes)?

This refers to calorie or protein supplements prescribed by a specialist. It does not include other supplements the patient takes without medical guidance. Here, the judgment of the specialist prevails: if the specialist determines that the patient needs these supplements, even if the patient does not take them, they should be scored as needing them.

RESPIRATORY FUNCTION

• Does the patient have a vital capacity greater than 80?

Use the most recent measurement, but always within the last 6 months prior to completing the questionnaire.

• Does the patient have a feeling of shortness of breath?

This should score dyspnea. It is important to ensure that it is dyspnea and not another symptom.



- **Can the patient cough effectively (expelling mucus) in daily life?**
 - *Incapable of doing it without help*: E.g., regularly needs to use cough assist device or requires help from parents or caregivers.
 - *Can do it with difficulty*: Usually clears mucus by coughing or clearing their throat, but with difficulty. Occasionally (during respiratory infections), they may need cough assist or help from others.
 - *Can do it without difficulty*: Expectorates without any issues.
- **Does the patient use cough assist device?**
 - *Daily*: Uses it three or more days a week.
 - *Occasionally*: Uses it twice a week or less, or only during respiratory infections.
 - *Never*.
- **Does the patient use ventilatory support (invasive and non-invasive ventilation)?**
More than 16 hours a day / 8-16 hours a day (at night and intermittently during the day) / Less than 8 hours a day (only for sleeping).

AXIAL FUNCTION

- **Does the patient have clinical signs of LMN (Lower Motor Neuron) in the axial region?**
In this case, the signs will be axial weakness (flexion/extension of the neck) or scoliosis (Cobb angle >15%).
- **Can the patient shake the head to say yes or no?**
In this item, the evaluator can ask the patient to perform the gesture, as the patient may not report difficulty in doing so. However, the evaluator may observe difficulty when interpreting the gesture. In case of a discrepancy between the report of the patient and the observation of the specialist (e.g., a patient who reports no issues but clearly has difficulty), the evaluator will score based on their own observation.
- **Does the patient need to rest their head on the headrest when sitting in the wheelchair?**
 - *Needs continuous support*: The patient cannot hold their head up on their own.
 - *Needs support at times*: They can hold their head up by themselves, but at times (e.g., on ramps, in a car, or after sitting for a while) they need support. Generally, if a patient has a headrest in their wheelchair, it is because they need to support their head, at least occasionally.
 - *Does not need support*: They do not have a headrest in the wheelchair.
- **Does the patient need to lean on the backrest when sitting in a wheelchair?**
 - *Needs continuous support*: The patient cannot stay seated without support (backrest or lateral support). This score applies when the patient is a non-sitter.
 - *Needs support at times*: They can sit by themselves, but at times (e.g., on ramps, in a car, or after sitting for a while) they need support.
 - *Does not need support*: They may lean back for comfort, but can remain seated for long periods without needing support.
- **Can the patient remain seated on the toilet?**
 - *Incapable of doing it without help*: The patient cannot use the toilet (they do it in bed or on an adapted chair), or they need someone (or a hoist) to support or keep them seated on the toilet.
 - *Can do it with difficulty*: The patient can sit on the toilet but requires external help or adaptations to stay seated (e.g., a stool, handle, etc.). Adaptations for standing up or sitting down on the toilet are not scored; only those needed to remain seated are.
 - *Can do it without difficulty*.

UPPER LIMB FUNCTION

- **Does the patient have clinical signs of LMN involvement in the upper limbs?**
Clinical signs: weakness, atrophy, areflexia, neurogenic tremor, fasciculations...



- **Can the patient use a computer?**

- *Incapable of doing it without help*: Does not use the computer or cannot use it (neither with a mouse nor a keyboard) without help from other people.
- *Can do it with difficulty*: Can use either the mouse or the keyboard, or can use both with substitute methods (e.g., typing with the help of a stick, adapted mouse or keyboard, etc.), or can use them without substitute methods, but more slowly than people without SMA.
- *Can do it without difficulty*: Although they do it differently, their efficiency and speed are similar to that of other people.

- **Can the patient press a switch on the wall (light, elevator, etc.)?**

You should ask about the switches the patient needs to use in their daily life (at home, work, etc.).

- *Incapable of doing it without help*.
- *Can do it with difficulty*: They struggle, need to use a stick for support, can do it at home but not in other unfamiliar places, etc.
- *Can do it without difficulty*.

- **Can the patient brush their teeth with any type of toothbrush?**

This refers only to brushing, not rinsing the mouth. It is rated independently of the type of toothbrush used (electric or manual). Again, when rating, ask the patient if they believe they do it as effectively and quickly as other people.

- **Can the patient eat and drink independently?**

This refers to bringing a spoon, fork, and glass to the mouth. The rating evaluates if the patient can do almost the entire task.

- *Incapable of doing it without help*: If the patient can perform part of the task, but the majority still requires assistance, it is rated as unable.
- *Can do it with difficulty*: If they do it slower, need to rest their elbows, or use adapted utensils or furniture. Also, if they can do it normally but need help in unusual circumstances (e.g., if they usually use a plastic cup with a straw at home but need help with a glass when dining out, or if they need help with one type of food like soup but not others).
- *Can do it without difficulty*: With the same speed and effectiveness as other people.

- **Can the patient use a knife and fork (to cut food)?**

Similar to the previous item, it evaluates what the patient does in their daily life.

- *Incapable of doing it without help*: If they can only cut soft foods, they are rated as unable to do it.
- *Can do it with difficulty*: This includes doing it more slowly, resting elbows, using adapted utensils, etc. If the patient can cut all foods at home with their knife but needs help when outside, it is rated as with difficulty. If the patient can cut all foods except particularly tough ones not part of their usual diet, it is rated as with difficulty.
- *Can do it without difficulty*: With the same speed and effectiveness as other people.

- **Does the patient move around their house in a non-motorized wheelchair?**

If the patient does not use a wheelchair at home but uses another type of chair (office chair or electric chair), but comes to the consultation with a manual wheelchair, they can be asked to demonstrate.

- *Incapable of doing it without help*: If the patient only has an electric wheelchair, it is rated this way, regardless of whether they say they could use a manual one.
- *Can do it with difficulty*: If they do it slower or need to rest occasionally.
- *Can do it without difficulty*: If the patient does not use a wheelchair or uses it without difficulty.

- **Can the patient reach objects on a high shelf?**

By “object,” it means an average-sized book (about 1 kg in weight) and by “high,” it refers to the height of the head of the patient (standing or sitting, as applicable).

- *Incapable of doing it without help*: They cannot do it, do not attempt to do it, or it is likely to fall.
- *Can do it with difficulty*: They struggle (may need to rest their arm on the shelf or use both hands), they manage to grab it, but it may fall more abruptly than usual, etc
- *Can do it without difficulty*: With the same speed and effectiveness as other people.

LOWER LIMB FUNCTION

• Can the patient roll over in bed?

In the regular bed of the patient and with their usual sheets/comforter.

- *Incapable of doing it without help*: If the patient can move a bit in bed but needs help to fully turn over when sleeping. In general, these patients need to be turned one or more times during the night by a caregiver.
- *Can do it with difficulty*: If the patient can move enough to not need help from others when sleeping, if they can do it in their bed but not in others, if they can usually do it but need some help in unusual circumstances (e.g., multiple blankets), if they need to grab onto the bed rail, etc.
- *Can do it without difficulty*: With the same speed and efficiency as other people.

• Can the patient walk around their house?

- *Incapable of doing it without help*: It will be scored as unable if the patient can walk but chooses not to (e.g. “they are afraid” to walk alone).
- *Can do it with difficulty*: If they can do it around the house but not outside, if they need any kind of orthosis or to lean against the wall, if they cannot walk at the same pace as others and have to be waited for, etc.
- *Can do it without difficulty*: With the same speed and effectiveness as other people.

• Can the patient wash their body in the shower?

It is important to ask about the legs, feet, and back. In their usual shower.

- *Incapable of doing it without help*: If they need help with their feet, back, etc.
- *Can do it with difficulty*: If they need to sit down, grab onto a rail, or use a brush. Also, if they need help entering or exiting the shower but can shower alone afterward, etc.
- *Can do it without difficulty*: With the same speed and effectiveness as other people.

• Can the patient go up a stretch of staircases?

Refers to 4-5 steps similar to those used in the HFMSE.

- *Incapable of doing it without help*: If the patient states they can climb a flight of stairs with difficulty, but they have not so in the last month or two, it is very likely that they are avoiding it by all possible means. In this case, the evaluator can ask the patient what they would do if they had the choice to climb a flight of stairs (4 or 5 steps) or use an alternative (e.g., a ramp or elevator), to help assess the score. They can also be asked to perform the task. Ultimately, the evaluator decides the score based on their clinical judgment.
- *Can do it with difficulty*: Needs a handrail, appears insecure, does not climb as fast as others.
- *Can do it without difficulty*: With the same speed and effectiveness as other people.

• Can the patient get up from the ground?

After a fall or if they sit on the floor. If there is doubt, the patient can be asked to perform the task.

- *Incapable of doing it without help*: Needs someone else to help them get up.
- *Can do it with difficulty*: Uses Gowers’ maneuver, grabs onto objects (but not people).
- *Can do it without difficulty*.

• Can the patient run?

Running is not walking fast. If the patient responds that they do not usually run, the evaluator can ask, “If you had to run to catch the bus, could you?” It is rare for a patient with SMA to be able to run.

- *Incapable of doing it without help*.
- *Can do it with difficulty*.
- *Can do it without difficulty*.



FATIGABILITY

- **If the patient has applied more effort than usual, does the fatigue last until the next day?**

In this case, the question is not referring to a daily activity, but rather something beyond the usual. Therefore, the response should refer to unusual situations (although not necessarily extraordinary activities). For example, working longer hours or walking a greater distance than usual, etc. In this question, the patient is allowed to reflect on more than the last 2-3 weeks, but never more than 6 months.

- *Often*: More than half of the time.
- *Sometimes*: Less than half of the time.
- *Never*.

- **Are there any activities that the patient has been able to do in the morning but cannot do in the afternoon or at night (e.g., experiencing energy depletion throughout the day)?**

This refers to daily life activities. Not being able to perform them means not being able to do them with the same ease, having to slow down and plan fewer activities in the afternoon or evening.

- *Often*: Three days a week or more.
- *Sometimes*: Two days a week or less.
- *Never*.

- **When the patient performs a repetitive daily task (such as writing or walking), do they notice that, after doing it for a while, they perform it increasingly worse or have to stop?**

- *Often*: Three days a week or more.
- *Sometimes*: Two days a week or less.
- *Never*.

- **Has the patient been able to maintain the level of energy and activity throughout the entire day?**

This question reflects the previous two and should be consistent with them.

- *Often*: Three days a week or more.
- *Sometimes*: Two days a week or less.
- *Never*.

OTHERS

- **Does the patient experience cramps?**

- *Often*.
- *Sometimes*.
- *Never*.

- **Does the functionality of the patient worsen with cold or humidity?**

- *A lot*.
- *Some*.
- *Not at all*.





Clinical Tool SMA LIFE

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of Adolescent and Adult Patients
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CLEAN
DATA

QUESTIONNAIRE¹

BULBAR FUNCTION

Does the patient have clinical signs of bulbar disease?

Yes No

Do not continue if the answer is negative

To what extent can the patient perform the following activities of daily living?

1	Make themselves understood when talking to an acquaintance?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
2	Make themselves understood when talking to a stranger?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
3	Make themselves understood when speaking on the phone?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
4	Can the patient talk for hours?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
5	Can the patient speak louder to make themselves understood in a noisy room?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
6	Can the patient drink liquids without choking or coughing?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
7	How long does it take the patient to complete a meal?		
	Same as the rest of the people (about 30 min)	Up to 15 minutes more than the rest (about 45 min)	More than 15 minutes more than the rest (more than 45 min)
8	Can the patient swallow pills?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
9	Does the patient experience excess saliva in the mouth?		
	Never	Occasionally	Continually
10	Does the patient need nutritional supplements (nutritional shakes)?		
	They do not need them	They are a nutritional supplement	They make up the majority of your diet

The tool presented is part of an ongoing study and is subject to modifications until final validation. The manuscript with the results of the Rasch analysis and intermediate validation will be published soon.

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RESPIRATORY FUNCTION

Does the patient have a vital capacity greater than 80?

Yes No

Do not continue if the answer is positive

To what extent can the patient perform the following activities of daily living?

1	Does the patient have a feeling of shortness of breath?		
	At rest	When carrying out activities or efforts	Never
2	Can the patient cough effectively (expelling mucus) in daily life?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
3	Does the patient use cough assist device?		
	Daily	Occasionally (with respiratory infections)	Never
4	Does the patient use ventilatory support (invasive and non-invasive ventilation)?		
	More than 16 h a day	8-16 h a day (at night and occasionally during the day)	Less than 8 h a day

AXIAL FUNCTION

Does the patient have clinical signs of LMN (Lower Motor Neuron) in the axial region?

Yes No

Do not continue if the answer is negative

To what extent can the patient perform the following activities of daily living?

1	Can the patient shake the head to say yes or no?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
2	Does the patient need to rest their head on the headrest when sitting in the wheelchair?		
	Needs continuous support	Needs support at times	Does not need support
3	Does the patient need to lean on the backrest when sitting in the wheelchair?		
	Needs continuous support	Needs support at times	Does not need support
4	Can the patient remain seated on the toilet?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty

UPPER LIMB FUNCTION

Does the patient have clinical signs of LMN involvement in the upper limbs?

Yes No

Do not continue if the answer is negative

To what extent can the patient perform the following activities of daily living?

1	Can the patient use a touchscreen phone or tablet?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
2	Does the patient use the electric chair joystick?		
	Incapable of doing it without help	Can do it with difficulty or needs an adapted joystick	Can do it without difficulty
3	Can the patient use a computer?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
4	Can the patient press a switch on the wall (light, elevator, etc.)?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
5	Can the patient brush their teeth with any type of toothbrush?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
6	Can the patient eat and drink independently?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
7	Can the patient use a knife and fork (to cut food)?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
8	Can the patient move around their house in a non-motorized wheelchair?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
9	Can the patient reach objects on a high shelf?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty

LOWER LIMB FUNCTION

To what extent can the patient perform the following activities of daily living?

1	Is the patient able to stay up?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
2	Can the patient roll over in bed?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
3	Can the patient walk around their house?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
4	Can the patient wash their body in the shower?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
5	Can the patient walk down the street on a flat surface?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
6	Can the patient go up a stretch of staircases?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
7	Can the patient get up from the ground?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty
8	Can the patient run?		
	Incapable of doing it without help	Can do it with difficulty (includes the use of substitute methods, but not help from third parties)	Can do it without difficulty

FATIGABILITY

To what extent can the patient perform the following activities of daily living?

1	If the patient has applied more effort than usual, does the fatigue last until the next day?		
	Often	Sometimes	Never
2	Are there any activities that the patient has been able to do in the morning but cannot do in the afternoon or at night (experience energy depletion throughout the day)?		
	Often	Sometimes	Never
3	When the patient performs a repetitive daily task (such as writing or walking), do they notice that, after doing it for a while, they perform it increasingly worse or have to stop?		
	Often	Sometimes	Never
4	Has the patient been able to maintain the level of energy and activity throughout the entire day?		
	Often	Sometimes	Never

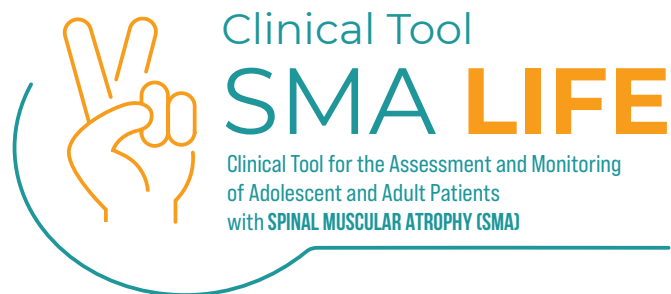
OTHERS

To what extent can the patient perform the following activities of daily living?

1	Does the patient experience cramps?		
	Often	Sometimes	Never
2	Does the functionality of the patient worsen with cold or humidity?		
	A lot	Some	Not at all

WARNING:

**DO NOT FORGET TO SAVE
THIS PDF FILE TO KEEP THE DATA**



This clinical tool has been designed within the context of the ML 43472 SMA Life study, coordinated by Dr. Juan Francisco Vázquez-Costa, neurologist and coordinator of the motor neuron disease unit at Hospital La Fe, and Dr. Mónica Povedano Panades, neurologist and coordinator of the motor neuron disease unit at Hospital Universitario de Bellvitge; with the collaboration of Dr. Mercedes Martínez Moreno, rehabilitation physician at Hospital Universitario La Paz, and Dr. María Grazia Cattinari, Medical Director at Fundame.

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