Cognitive, emotional and behavioral consequences of stroke

# List of alerts for caregivers

## Instructions on using the list of alerts

Research has shown that a large number of patients who've experienced a stroke have vague complaints or say that 'things do not work anymore'. Things that used to be simple and logical, now seem more difficult. For example, the patient complains that contacts with others are uncomfortable or that daily operations yield problems. Such complaints may also be put forward by the partner or other relatives. The patient is no longer like before, is easily angered or is sitting in a quiet area all day. You can get the feeling that something is not right. The problems in a family situation can accumulate.

These symptoms may be related to the stroke. Specific questions about the nature and severity of these complaints can give you a better understanding of the situation. This alert list is developed to support you in asking the right questions. The list is not intended to be a diagnostic instrument. On the basis of the results, you can take into account the effects of the stroke, or if necessary, you can specifically refer for further diagnosis and treatment by a psychologist and/or rehabilitation physician.

# Method

Make an appointment with the patient and possibly the partner or other close relatives, to talk about these issues further. Take your time for this interview, because there can be a lot of emotion from those involved. Use the list of alerts to shape your interview and to register observed changes. Having an interview on the basis of this list usually takes about 10 minutes. If you have the interview with the patient and a relative of the patient, it is important that you make it clear in advance that you want to hear the opinion of the patient first and then that of the relative. In addition it may help to explain that there may be differences of opinion.

The list includes 22 items which might indicate underlying disorders on cognitive, emotional and behavioral area. For each item, you can specify:

- 1. Whether this problem is clearly present or absent, it is inconvenient or not or doubtful if you are not sure; try to get as many clear answers as possible.
- 2. Who recognizes this problem: the patient, the partner or other relative or yourself; you note it by filling at the corresponding item a '**P**' for the the patient, an '**R**' for a relative or friend and an 'I' for interviewer if you yourself detected the problem.

The items in the list are explained on the opposite page. For each item an example is given by which you can get a judgment. These examples serve to guide the conversation. At the end of the list are two blank items (number 23 and 24); here you can add other notable problems or behaviour that have not yet been addressed.

On the back of the form there is space for comments or other information that you consider important.

## Please note

Problems in cognitive, emotional and behavioral areas are common after a stroke (CVA). It is therefore advisable to have a conversation with the patient and or his family about these issues regularly. It is advisable not to wait until the problems have piled, but take an active part by paying attention to this issue with every stroke patient who is with you for care, at fixed intervals after the stroke, for example, every six months.



## Explanatory notes on the items of the list of alerts

Since the occurrence of the stroke, the patient has:

## 1. Trouble to do two things at once

Question: "Is it difficult for you to do two things at once?" The patient is not able to cook and talk at the same time, or walk and talk at the same time; or answer any questions while he / she takes off his jacket and sits down.

## 2. Trouble to keep focused

Question: "Are you able to concentrate?" The patient is easily distracted; or can't keep the conversation flowing; or is disturbed by outside noises or other people in the room; or may not be able to read a newspaper article or follow the news on TV up to the end.

## 3. Trouble to keep up with everything, become slower

Question: "Do you feel that everything is going too fast, for example watching TV? Have you become slower in your way of doing things?" The patient feels that since the stroke everything seems to go very quickly. It can be difficult to follow a TV program, a conversation or other information from the outside world because of the pace. it can occur that the patient responds slowly.

## 4. Trouble to remember new information

Question: "Do you often forget what you have just been told?" The patient has trouble remembering where he put things, or remember a phone number long enough to enter it. The patient has trouble learning new things, such as the use of equipment.

## 5. Trouble to remember information from longer ago, forgetful

Question: "Have you become forgetful? Do you sometimes forget appointments?" The patient often forgets appointments, or doesn't remember your name or the names of the (grand)children; or tells the same story over and over again or doesn't remember what he did yesterday or asks about the same information over and over again.

## 6. Trouble to take initiative

Question: "Are tasks waiting to be done of do you have trouble starting them?" The patient does not ask you any questions him-,or herself; or has trouble starting daily activities, like domestic activities or hobbies.

## 7. Trouble planning or organizing things

Question: "Do you have trouble planning or arranging daily activities?" The patient can't prepare, organize or perform correctly any activities. The patient lacks flexibility and overview, or doesn't do the home administration (anymore), or doesn't cook (anymore) because he/she can't do it anymore or is less efficient when he/she does do it.

## 8. Trouble with daily implementation of concrete activities (not by paralysis)

Question: "Do you often use objects in a wrong way? Or does it happen that you don't remember the order?" The patient has difficulty with (un-)dressing, domestic or creative activities; or has difficulty with the sequence of operations.



#### 9. Reduced conscience of time

Question: "Do you often make mistakes about the time or how long something takes?" The patient does not know today's date; or does not know what time it is or how long the conversation has taken.

## 10. Reduced conscience of place, space or person

Question: "Do you often get lost? Or do you often fail to remember whom you are talking to?" The patient doen not remember where he/she is or often gets lost inside home or outside. He/She does not know who you are or does not remember the reason for the visit to you or from you.

## 11. Trouble to understand spoken and/or written language

Question: "Do you have trouble reading the paper or follow a conversation?" The patient does not understand what you are saying, or doesn't understand the newspaper or other written text. Or you do not get appropriate responses to your questions.

## 12. Trouble to talk or write

Question: "Do you often have difficulty speaking or writing?" The patient often can't think of the right word; or uses words with the wrong meaning. Or the patient writes down words or sentences incorrectly or pronounces words incorrectly.

## 13. No attention to part of the body or the environment

Question: "Does it happen that you forget or don't see things on that are on your left?" The patient often runs into objects, for example people in the street, or door posts, or forgets something that is on the left side of the body, for example a part of the meal.

## 14. Gloomy, dejected, depressed

Question: "Do you often feel sad or depressed?" The patient cries a lot or is often sad, or does not have interest or pleasure in life anymore.

## 15. Anxiety

Question: "Have you become more anxious?" The patiënt is afraid to get a stroke again, or afraid of being left alone, or afraid to go out by him-/herself.

#### 16. More self-centered, less social contacts

Question: "Are you more focused on yourself? Do you have less social contacts?" The patient is introverted, isolates him-/herself or has less interest in others.

#### 17. Unrealistic expectations

Question: "Are you often confronted with the fact that you don't succeed as good as before in doing certain things?" The patient sees the meaning or usefulness of things no longer, or puts excessive demands on him- or herself or on others, or is very focused on repair or healing (while the stroke has occurred more than a year ago).



#### 18. Easily emotional, crying faster

Question: "Are your crying more easily, are you moved faster?" The patient has the idea that tears come more easily than before the stroke.

#### 19. Easily irritated, irritable

Question: "Are you more easily irritated, more excitable?" The patient often responds very fierce, especially if things do not go the way he/she wants.

20. Indifferent, cool, expressing feelings less

Question: "Have you become indifferent?" The patient ignores things, or shows less interest in other people or events.

## 21. Disinhibition, difficulty controlling behaviour

Question: "Do you sometimes feel like the brake is off?" The patient has little control on the behaviour, for example emotions, verbal expressions, food/drink, sexuality or spending money.

## 22. Faster and more often tired

Question: "Are you more often and faster tired nowadays?" The patient is quickly tired both physically and mentally, needs more sleep.

## 23. Additional problems

Question: "Are there other issues that have not been discussed here?"



# Signaling cognitive, emotional and behavioral consequences

Name patient:	_ m/f Date of birth	_ Date of Stroke
Present at the interview:	Relation to the part	tient:

The alert List was completed by: \_\_\_\_\_ Date: \_\_\_ - \_\_\_ - \_\_\_\_

In the table below: mark with: 'P' for Patient, 'R' for Relative or friend, 'I' for Interviewer

Problem	Does the pro	blem occur sind	ce the st	roke?	
Since the stroke the patient has:	Yes, it is	Yes, but not	No	Not	
	very	troublesome		sure	
	troublesome				
Cognition					
1. Trouble to do two things at once					
2. Trouble to keep focused					
3. Trouble to keep up with everything,					
become slower					
4. Trouble to remember new information					
5. Trouble to remember information from					
longer ago, forgetful					
6. Trouble to take initiative					
7. Trouble planning or organizing things					
8. Trouble with daily implementation of					
concrete activities (not by paralysis)					
9. Reduced conscience of time					
10. Reduced conscience of place, space or					
person					
11. Trouble to understand spoken and/or					
written language					
12. Trouble to talk or write					
13. No attention to part of the body or the					
environment					
Emotions and behaviour	•				
14. Gloomy, dejected, depressed					
15. Anxiety					
16. More self-centered, less social contacts					
17. Unrealistic expectations					
18. Easily emotional, crying faster					
19. Easily irritated, irritable					
20. Indifferent, cool, expressing feelings less					
21. Disinhibition, difficulty controlling					
behavior					
22. Faster and more often tired					
Additional problems					
23.					
24.					



Remarks and additional information:

