

eAppendix 1 Questionnaire

Compensation strategies to improve walking in persons with Parkinson disease

PART 1

1. Do you experience walking difficulties due to Parkinson's disease?
 - a. No, I do not experience difficulties walking
 - b. Yes, I do experience difficulties walking but it does not affect my ability to perform my usual daily activities
 - c. Yes, I do experience difficulties walking and it negatively affects my ability to perform my usual daily activities

Freezing of gait is the feeling that your feet are transiently glued to the floor while trying to initiate walking, making a turn or when walking through narrow spaces or in crowded places. Sometimes it can be accompanied with trembling of the legs and small shuffling steps.

2. Did you experience freezing episodes over the past month?
 - a. I have not experienced such a feeling or episode over the past month
 - b. I have experienced such a feeling or episode over the past month
3. How frequently do you experience freezing episodes?
 - a. Less than once a week
 - b. Not often, about once a week
 - c. Often, about once a day
 - d. Very often, more than once a day
4. How frequently do you experience freezing episodes during turning?
 - a. Never
 - b. Rarely, about once a month
 - c. Not often, about once a week
 - d. Often, about once a day
 - e. Very often, more than once a day
5. How long is your longest freezing episode during turning?
 - a. Very short, 1 sec
 - b. Short, 2 - 5 sec
 - c. Long, between 5 and 30 sec
 - d. Very long, unable to walk for more than 30 sec
6. How frequently do you experience episodes of freezing when initiating the first step?
 - a. Never
 - b. Rarely, about once a month
 - c. Not often, about once a week
 - d. Often, about once a day
 - e. Very often, more than once a day

7. How long is your longest freezing episode when initiating the first step?
 - a. Very short, 1 sec
 - b. Short, 2-5 sec
 - c. Long, between 5 and 30 sec
 - d. Very long, unable to walk for more than 30 sec

8. How disturbing are the freezing episodes for your daily walking?
 - a. Not at all
 - b. Very little
 - c. Moderately
 - d. Significantly

9. Do the freezing episodes cause feelings of insecurity and fear of falling?
 - a. Not at all
 - b. Very little
 - c. Moderately
 - d. Significantly

10. Are your freezing episodes affecting your daily activities? (Rate the impact of freezing on daily activities only. Not the impact of the disease in general)
 - a. Not at all, I continue doing things as normal
 - b. Mildly, I avoid only few daily activities
 - c. Moderately, I avoid a significant amount (about half) of daily activities
 - d. Severely, I am very restricted in carrying out most daily activities

11. How many times did you fall in the past 12 months?
 - a. I did not fall
 - b. Once
 - c. Once every month
 - d. Once every week
 - e. Daily

12. Did you sustain any injuries from falling in the past 12 months?
 - a. I sustained no injury
 - b. I sustained an injury that did not need to be treated
 - c. I sustained an injury that needed to be treated

PART 2

Persons with Parkinson's disease and difficulties walking, can use compensation strategies to improve their ability to walk. There are many different types of strategies, which can be subdivided into seven separate categories. In this part of the questionnaire we would like to make an inventory of whether you know and use these compensation strategies.

CATEGORY I – EXTERNAL CUEING

The first category of compensation strategies involves external cueing. During external cueing, visual, auditory or tactile stimuli are used. These stimuli are usually rhythmic.

Examples include:

- *Walking at the rhythm of a metronome;*
- *Walking at the beat of music;*
- *Walking while stepping over lines pasted to the floor, or a certain pattern on the floor;*
- *Stepping over someone else's foot.*

13. Did you know of the existence of external cueing to improve walking?

- a. Yes, I have heard of it before
- b. No, I have never heard of it before

14. How did you hear about the existence of external cueing?

- a. Through my medical doctor
- b. Through my physiotherapist (physical therapist)
- c. Through my occupational therapist
- d. I have read about it
- e. I came up with it myself
- f. Through another source

15. Please fill in a description of the source:

.....

16. Have you ever tried a form of external cueing?

- a. Yes, I have tried a form of external cueing and I still use it in my daily life
- b. Yes, I have tried a form of external cueing, but I do not use it in my daily life (anymore)
- c. No, I have never tried a form of external cueing

17. Please describe the type of external cueing that you use or used:

.....

18. The effect of external cueing may vary depending on the situation or context in which it is used. **Please indicate the effect of external cueing on your ability to move for the different situations described below:**

	External cueing improves my ability to move	External cueing has no effect on my ability to move	External cueing worsens my ability to move	I have never used external cueing in this situation
When taking your first step after getting up from a chair	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking through a doorway	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When making a turn	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When attempting to stop walking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
During the performance of a purposeful daily activity (eg. getting dressed, kitchen activities)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking while talking to someone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking while carrying something (eg. a drink, a meal)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In a situation of time pressure (eg. going to the toilet, crossing the street)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking in a small or narrow space (eg. walking in the bathroom, in a room packed with furniture)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking in a crowded area (eg. a busy market place)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outdoors (eg. when walking on the street)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

CATEGORY II – INTERNAL CUEING

Rather than being guided by external cues, persons with Parkinson’s disease can also use internal cues to improve their ability to walk. Internal cues can help to focus attention on (a specific part of) walking.

Examples include:

- *Counting and making a heel strike at every count.*

19. Did you know of the existence of internal cueing to improve walking?

- a. Yes, I have heard of it before
- b. No, I have never heard of it before

20. How did you hear about the existence of internal cueing?

- a. Through my medical doctor
- b. Through my physiotherapist (physical therapist)
- c. Through my occupational therapist
- d. I have read about it
- e. I came up with it myself
- f. Through another source

21. Please fill in a description of the source:

.....

22. Have you ever tried a form of internal cueing?

- a. Yes, I have tried a form of internal cueing and I still use it in my daily life
- b. Yes, I have tried a form of internal cueing, but I do not use it in my daily life (anymore)
- c. No, I have never tried a form of internal cueing

23. Please describe the type of internal cueing strategies that you use or used:

.....

24. The effect of internal cueing may vary depending on the situation or context in which it is used. **Please indicate the effect of internal cueing on your ability to move for the different situations described below:**

	Internal cueing improves my ability to move	Internal cueing has no effect on my ability to move	Internal cueing worsens my ability to move	I have never used internal cueing in this situation
When taking your first step after getting up from a chair	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking through a doorway	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When making a turn	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When attempting to stop walking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
During the performance of a purposeful daily activity (eg. getting dressed, kitchen activities)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking while talking to someone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking while carrying something (eg. a drink, a meal)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In a situation of time pressure (eg. going to the toilet, crossing the street)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking in a small or narrow space (eg. walking in the bathroom, in a room packed with furniture)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking in a crowded area (eg. a busy market place)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outdoors (eg. when walking on the street)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

CATEGORY III - CHANGING BALANCE REQUIREMENTS

A third compensation strategy involves a change of balance requirements during gait. With this strategy, you change walking conditions to make it easier to move your weight from one leg to the other, or you use tools (eg. a walker) to reduce the need to make weight shifts.

Examples include:

- *Shifting your weight to one leg before taking a step;*
- *Making wider turns;*
- *Using a wheeled-walker.*

25. Did you know of the existence of changing the balance requirements to improve walking?
a. Yes, I have heard of it before
b. No, I have never heard of it before

26. How did you hear about the existence of the 'changing the balance requirements' strategy?
a. Through my medical doctor
b. Through my physiotherapist (physical therapist)
c. Through my occupational therapist
d. I have read about it
e. I came up with it myself
f. Through another source

27. Please fill in a description of the source:
.....

28. Have you ever tried a form of changing the balance requirements?
a. Yes, I have tried a form of changing the balance requirements and I still use it in my daily life
b. Yes, I have tried a form of changing the balance requirements, but I do not use it in my daily life (anymore)
c. No, I have never tried a form of changing the balance requirements

29. Please describe the form of changing the balance requirements that you use or used:
.....

30. The effect of changing the balance requirements may vary depending on the situation or context in which it is used. **Please indicate the effect of 'changing the balance requirements' on your ability to move for the different situations described below:**

	Changing the balance requirements improves my ability to move	Changing the balance requirements has no effect on my ability to move	Changing the balance requirements worsens my ability to move	I have never used 'changing the balance requirements' in this situation
When taking your first step after getting up from a chair	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking through a doorway	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When making a turn	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When attempting to stop walking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
During the performance of a purposeful daily activity (eg. getting dressed, kitchen activities)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking while talking to someone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking while carrying something (eg. a drink, a meal)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In a situation of time pressure (eg. going to the toilet, crossing the street)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking in a small or narrow space (eg. walking in the bathroom, in a room packed with furniture)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking in a crowded area (eg. a busy market place)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outdoors (eg. when walking on the street)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

CATEGORY IV - ALTERING THE MENTAL STATE

Alteration of the mental state is the fourth category of compensation strategies that might improve walking in persons with Parkinson's disease. This strategy stimulates alertness and helps to focus attention. In an extreme form, this strategy occurs in stressful situations: a classic example is patients' improved ability to walk during an earthquake. Obviously, life-threatening situations cannot be used as a compensation strategy on a daily basis. However, improvements of gait impairments owing to increased motivation or relaxation might have a similar effect.

An example could be:

- *Relaxation through breathing exercises before starting to walk.*

31. Did you know of the existence of altering the mental state to improve walking?

- a. Yes, I have heard of it before
- b. No, I have never heard of it before

32. How did you hear about the existence of the 'altering the mental state' strategy?

- a. Through my medical doctor
- b. Through my physiotherapist (physical therapist)
- c. Through my occupational therapist
- d. I have read about it
- e. I came up with it myself
- f. Through another source

33. Please fill in a description of the source:

.....

34. Do you feel stress or anxiety have a negative effect on your ability to walk?

- a. Yes, stress and anxiety negatively affect my gait
- b. No, stress and anxiety have no effect on my gait

35. Do you avoid stressful situations because it has a negative effect on your ability to walk?

- a. Yes, I try to avoid stressful situations because of this
- b. No, I do not avoid stressful situations because of this

36. Have you ever tried a form of altering the mental state?

- a. Yes, I have tried a form of altering the mental state and I still use it in my daily life
- b. Yes, I have tried a form of altering the mental state, but I do not use it in my daily life (anymore)
- c. No, I have never tried a form of altering the mental state

37. Please describe the form of altering the mental state that you use or used:

.....

38. The effect of altering the mental state may vary depending on the situation or context in which it is used. **Please indicate the effect of ‘altering the mental state’ on your ability to move for the different situations described below:**

	Altering my mental state improves my ability to move	Altering my mental state has no effect on my ability to move	Altering my mental state worsens my ability to move	I have never used ‘altering the mental state’ in this situation
When taking your first step after getting up from a chair	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking through a doorway	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When making a turn	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When attempting to stop walking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
During the performance of a purposeful daily activity (eg. getting dressed, kitchen activities)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking while talking to someone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking while carrying something (eg. a drink, a meal)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In a situation of time pressure (eg. going to the toilet, crossing the street)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking in a small or narrow space (eg. walking in the bathroom, in a room packed with furniture)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking in a crowded area (eg. a busy market place)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outdoors (eg. when walking on the street)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

CATEGORY V - MOTOR IMAGERY OR ACTION OBSERVATION

Motor imagery and action observation are the fifth category of compensation strategies to improve gait in persons with Parkinson's disease. During action observation, you observe someone else walking and try to mimic the walking pattern. During motor imagery, you walk while you visualize someone walking.

39. Did you know of the existence of motor imagery and action observation to improve walking?
- a. Yes, I have heard of it before
 - b. No, I have never heard of it before

40. How did you hear about the existence of motor imagery and action observation?
- a. Through my medical doctor
 - b. Through my physiotherapist (physical therapist)
 - c. Through my occupational therapist
 - d. I have read about it
 - e. I came up with it myself
 - f. Through another source

41. Please fill in a description of the source:
.....

42. Have you ever tried a form of motor imagery or action observation?
- a. Yes, I have tried a form of motor imagery or action observation and I still use it in my daily life
 - b. Yes, I have tried a form of motor imagery or action observation, but I do not use it in my daily life (anymore)
 - c. No, I have never tried a form of motor imagery or action observation

43. Please describe the form of motor imagery or action observation that you use or used:
.....

44. The effect of motor imagery and action observation may vary depending on the situation or context in which it is used. **Please indicate the effect of 'motor imagery and action observation' on your ability to move for the different situations described below:**

	Motor imagery or action observation improves my ability to move	Motor imagery or action observation has no effect on my ability to move	Motor imagery or action observation worsens my ability to move	I have never used motor imagery or action observation in this situation
When taking your first step after getting up from a chair	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking through a doorway	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When making a turn	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When attempting to stop walking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
During the performance of a purposeful daily activity (eg. getting dressed, kitchen activities)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking while talking to someone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking while carrying something (eg. a drink, a meal)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In a situation of time pressure (eg. going to the toilet, crossing the street)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking in a small or narrow space (eg. walking in the bathroom, in a room packed with furniture)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking in a crowded area (eg. a busy market place)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outdoors (eg. when walking on the street)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

CATEGORY VI – ADAPTING A NEW WALKING PATTERN

The sixth category of compensation strategies is the adaption of a new walking pattern. Usually, these movements are not completely new but have been learned previously. Examples of adopting a new walking pattern include: walking with the knees lifted high, walking as if you are skating, making a cross pass, walking backwards, walking sideways, climbing stairs, jumping, and running.

45. Did you know of the existence of adapting a new walking pattern to improve walking?
- a. Yes, I have heard of it before
 - b. No, I have never heard of it before

46. How did you hear about the existence of the 'adaption of a new walking pattern' strategy?
- a. Through my medical doctor
 - b. Through my physiotherapist (physical therapist)
 - c. Through my occupational therapist
 - d. I have read about it
 - e. I came up with it myself
 - f. Through another source

47. Please fill in a description of the source:
.....

48. Have you ever tried adapting a new walking pattern?
- a. Yes, I have tried adapting a new walking pattern and I still use it in my daily life
 - b. Yes, I have tried adapting a new walking pattern, but I do not use it in my daily life (anymore)
 - c. No, I have never tried adapting a new walking pattern

49. Please describe the new walking pattern that you use or used:
.....

50. The effect of adapting a new walking pattern may vary depending on the situation or context in which it is used. **Please indicate the effect of adapting a new walking pattern on your ability to move for the different situations described below:**

	Adapting a new walking pattern improves my ability to move	Adapting a new walking pattern has no effect on my ability to move	Adapting a new walking pattern worsens my ability to move	I have never adapted a new walking pattern in this situation
When taking your first step after getting up from a chair	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking through a doorway	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When making a turn	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When attempting to stop walking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
During the performance of a purposeful daily activity (eg. getting dressed, kitchen activities)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking while talking to someone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking while carrying something (eg. a drink, a meal)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In a situation of time pressure (eg. going to the toilet, crossing the street)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking in a small or narrow space (eg. walking in the bathroom, in a room packed with furniture)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When walking in a crowded area (eg. a busy market place)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outdoors (eg. when walking on the street)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

CATEGORY VII - ALTERNATIVES TO NORMAL WALKING

The final category of compensation strategies for walking difficulties caused by Parkinson's disease is using other means than walking to move forward.

Examples include:

- *Riding a bicycle;*
- *Ice skating;*
- *Using a scooter;*
- *Roller skating;*
- *Skateboarding.*

51. Have you ever tried alternatives to normal walking?

- a. Yes, I have tried alternatives to normal walking and I still use it in my daily life
- b. Yes, I have tried alternatives to normal walking, but I do not use it in my daily life (anymore)
- c. No, I have never tried alternatives to normal walking.

52. Please provide a description of the alternatives that you use or have used to move forward:

.....

OTHER CATEGORIES

53. Were you ever obliged to switch to different compensation strategies over time, because the effect of a particular strategy tapered off over time?

- a. Yes, I was obliged to switch to different strategies over time
- b. No, I am still using my original strategies
- c. I have never used compensation strategies

54. Which compensation strategies did you have to switch out? And why?

.....

55. Do you use compensation strategies that were not mentioned in this questionnaire.?

- a. Yes, I do
- b. No, I do not

56. Please provide a description of the strategies that you use:

.....

PART 3

57. Clinicians and therapists (eg. physiotherapists, occupational therapists, rehabilitation physicians, neurologists) can offer advice on the use of compensation strategies. Have you ever received advice on the use of compensation strategies?

- a. Yes, I have received advice that was focused on the use of compensation strategies
- b. No, I have not received advice that was focused on the use of compensation strategies

58. Would you be interested to receive (additional) interventions to learn all available compensation strategies?

- a. Yes, I would be interested
- b. No, I would not be interested.

59. I would not be interested in receiving (additional) interventions to learn all available compensation strategies, because:

.....

