Questionnaire 1

General information:

Age: _____ Gender: ☐ male ☐ female

Onset of illness: _____ Therapy with botulinum toxin since: _____ Last botulinum toxin injection on: _____

Medication: _____

Accompanying therapies to botulinum toxin: (please check each ☐ mark with a cross if applicable)

1) **No concomitant therapy** ☐

2) **Physiotherapy specially designed for dystonia** ☐

For example:
Exercises focusing on the correction of dystonic malposition; stretching of the dystonic muscles with subsequent passive movement; so-called "Bleton" method: strengthening of the muscles contrary to the (dystonic) direction of pull

Description of the method used (physiotherapist part):

……

……

……

3) **„General" physiotherapy and not specifically designed for dystonia** ☐

Description of the method used (physiotherapist part):

a) Posture correction O (____ % of therapy time)
b) Relaxation O (____ % of therapy time)
c) Muscle stretching O (____ % of therapy time)
d) Passive mobilization O (____ % of therapy time)
e) Massage O (____ % of therapy time)

4) **Other therapies:** ☐

Relaxation exercises (e.g. progressive muscle relaxation) ○
Psychotherapy (e.g. cognitive behavioral therapy) ○
Electrotherapy (e.g. transcutaneous electrical stimulation TENS) ○
EMG biofeedback training ○
Other: _____ ○

Frequency (e.g. how often per week for how many hours):

___ per week; each ____ hours

Questionnaire 2

How often did the following statements apply to you within the last 14 days due to the dystonia disorder?

Please check one answer option and answer each question if possible.

1) Did you have problems reading or watching TV?
   never ○ occasionally ○ sometimes ○ often ○ always ○

2) Did you have difficulties doing activities that you wanted to do? (e.g. leisure, hobby)?
   never ○ occasionally ○ sometimes ○ often ○ always ○

3) Did you have difficulty controlling the symptoms of your illness when you were stressed or upset?
   never ○ occasionally ○ sometimes ○ often ○ always ○

4) Have you suffered from pain/burning in the face, head or neck area?
   never ○ occasionally ○ sometimes ○ often ○ always ○

5) Did pain or a pulling sensation prevent you from falling asleep?
   never ○ occasionally ○ sometimes ○ often ○ always ○

6) Did you have difficulty performing fine tasks with your fingers (e.g. writing, threading)?
   never ○ occasionally ○ sometimes ○ often ○ always ○

7) Did you avoid situations where many people were present (e.g. social events)?
   never ○ occasionally ○ sometimes ○ often ○ always ○

8) Did you feel uncomfortable in public because of your illness?
   never ○ occasionally ○ sometimes ○ often ○ always ○

9) Did you have the feeling that you had to hide your illness from others?
   never ○ occasionally ○ sometimes ○ often ○ always ○

10) Have you thought about how other people react to you?
    never ○ occasionally ○ sometimes ○ often ○ always ○

11) Have you been worried about your future?

never ○ occasionally ○ sometimes ○ often ○ always ○

12) Did you feel anxious?

never ○ occasionally ○ sometimes ○ often ○ always ○

13) Did you feel down or depressed?

never ○ occasionally ○ sometimes ○ often ○ always ○

14) Did you feel sad or on the verge of tears?

never ○ occasionally ○ sometimes ○ often ○ always ○

15) Were you angry or bitter?

never ○ occasionally ○ sometimes ○ often ○ always ○

16) Did your illness make you feel isolated or lonely?

never ○ occasionally ○ sometimes ○ often ○ always ○

17) Have you had problems with close friends or family as a result of your illness?

never ○ occasionally ○ sometimes ○ often ○ always ○

18) Did you feel insecure or tense when dealing with people you didn't know?

never ○ occasionally ○ sometimes ○ often ○ always ○

19) Did you have difficulties coping with the demands placed on you at work or at home?

Employed: yes ○ *no* ○

not at all ○ low ○ moderate ○ strong ○ very strong ○

20) Did you feel impaired in traffic?

not at all ○ low ○ moderate ○ strong ○ very strong ○

21) Did you feel affected by pain/burning in the face, head or neck area?

not at all ○ low ○ moderate ○ strong ○ very strong ○

22) Have you had the feeling of being less attractive on the outside?

not at all ○ low ○ moderate ○ strong ○ very strong ○

23) Has the dystonia disorder put a strain on your family life?

not at all ○ low ○ moderate ○ strong ○ very strong ○

24) Has the dystonia disorder affected your partner relationship?

Relationship: yes ○ *no* ○

not at all ○ low ○ moderate ○ strong ○ very strong ○

Pain scale:

How would you rate your pain in connection with cervical dystonia (e.g. accompanying head, neck, shoulder and back pain)? **please check the number**

0 (no pain) 10 (strongest imaginable pain)

0 1 2 3 4 5 6 7 8 9 10

In the case of concomitant therapy: How do you rate the pain after the therapy?

a) ____ % improvement O

b) ____ % deterioration O