

TRAINING MANUAL

SPINAL CORD INJURY

Basic Psychological Knowledge
and Skills for persons
living with SCI

**HANDICAP
INTERNATIONAL**



Spinal Cord Injury

Basic Psychological Knowledge and Skills for staff working for persons living with SCI

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This document is destined for the following health staff :
**Doctors - Nurses – Physical therapists – Occupational
therapists**
Psychological consultant
Peer counsellors
**Health staff who are helping patients with spinal cord
injury and their family members.**

TABLE OF CONTENTS

1. Trauma
2. Somatic Symptoms or Bodily Complaints
3. Loss Processes after Spinal Cord Injury
4. General anxiety and stress
 - Acute Stress Disorder
 - Post Traumatic Stress Disorder
5. Cycle of Fear
6. Depression
7. Signs that can lead to Suicide
8. Causes of Depression
9. Cycle of Depression
10. Treatment Options
 - a. Basic Psychological Counselling Skills
 - b. Announcement of bad news
 - c. Use of Depression, Anxiety and Stress Score (DASS)
 - d. Pharmacology used for Treatment

1. Trauma

What is trauma?

Trauma is the consequence caused by extremely scaring and frightening events that pose a threat to the safety of a person's life. It can also be caused by witnessing events that harmed other persons.

Different situations which can lead to traumas:

1. Disasters: Tsunami, forest fires, flood, earthquake, storms and hurricanes etc.....
2. Accidents: traffic accidents, labour accidents etc.....
3. Crimes/ Violence: occurring in public, on the street or at house
4. Terrorist attacks

2. Somatic Symptoms or Bodily Complaints

- Being exhausted
- Sleeping difficulties and waking up early
- Feeling pain at many body functions (like sore joints)
- Difficulties in remembering events
- Sadness or depression
- Difficulties in concentrating

3. Loss processes after Spinal Cord Injury

At the beginning of the spinal cord injury phase, the patient usually experiences a shock right after the accident .It is the start of the loss process that will impact their daily life from then on. Their life line has made a turn of 180 degrees. The person had to realise that he will never be able to have physical recovery again. They will have feelings of loss, sadness and prolonged fear for periods in row .

Loss processes are a reality through which the patient must go before their psychological condition is stabilised. By helping and explaining them to understand that what happened to them could happen to everyone and advising them on how to manage current difficulties, they will accept their new situation more easier.

Loss processes cause much sadness, depressions and anxiety. The phases go as this :

Not accepting what happened can be called having **“a Shock”**: After the accident, the person with SCI usually stays in denial with what happened to him. There is always one thing on their mind: “This can’t have happened to me”. This person will usually show the following symptoms :

- No emotions
- No response when asked something by someone
- Concentration difficulties
- Memory difficulties

Due to a sudden change in his life, this person will be prone to stress and anxiety when he realizes that he is being saved through the use of many kinds of medical equipment on him as well as perfusions and ventilation machines he is depending on. Confusion, alarm and strong fears follow because they worry about their future. What is going to happen? They wonder if they still are alive or dead or will be able to recover.

Negation phase: the person does not believe in what is happening to him. The person with SCI usually negates his condition. **This Negation** helps the patient to keep him away from suffering many emotions that occur at the same time. Especially, in case of paralysis and disability. They always say to themselves that “I can’t and will not become a disabled person”. After the reality, that they are losing control of their body functions (toilet and grooming) as well as their body movements the **negation** is a logical phase that a person with SCI goes through, because it helps them to release his tension , not only for himself but also for

his family members who are facing also many difficulties during this moment. However, negation doesn't mean that they will refuse every help. They will accept some of it, only what they do want to hear. For example: one day Mr Ba said to a nurse who is taking care of him that he just needed one or two weeks more for sitting up and walking again. He was re-assuring the nurse about this . Most of the patient will overcome this phase when they observe other patients who are around them everyday.

Bargaining or negotiation: They usually talk to themselves that:” If I try my best I will go over problems”, “If God blesses me and helps me out of the current miseries I am ready to worship a pig”. They hope there will be a miracle to help them out of the condition caused from Spinal Cord Injury. “If I could walk again I would...” There is one thing that should be noticed that family members and friends shouldn't comfort the patient too much because it will result in the person with SCI to stay longer in Negation or Bargaining (Negotiation) phase.

Anger: They usually talk to themselves that: “Why this accident happened to me? I can't become a disabled person. I will prove to everyone that all assessments from doctors were wrong”. However, all of these defences become useless because the reality is still there. The reality is that they can't move now. All of the daily living activities such as eating,

drinking, dressing, washing, going to the toilet needs help from the others. Once they realize that it is impossible to change the condition, they usually blame it on unfairness of life:” Life is very unfair, maybe I was punished because of my mistakes in the past”. They get angry with people around them, persons who takes care of them, doctors and health staff even with themselves. Sometimes it is difficult to understand the reason why they get angry. Someone can feel very angry inside but can’t express it in words. They usually get upset inside without saying it but don’t want to let people know about it. Sometimes they take the anger out on doctors and health staff by not following treatments indicated. As a caretaker or health staff for persons with SCI, You should Notice that:” Do not let the patient’s emotion affect you”. If you are taking care of them as doctors, nurses or other health staff, you should remember that emotions of anger are part of the loss processes which most of the persons with SCI have to go through and come over with.

Sadness/Depression: Emotion of the patient that changes from feeling good to being sad/ depressive. They think that “Everything is depressing”, “They just want to die to be released from people around them and from being sad/ depressive. They usually say to themselves: “I’m a burden for everybody “This usually happens when the patient realizes that they

don't have any chance to be recover, they can't walk anymore and then they start to accept their disability. Being sad/ depressive can occur many times in the loss process and the rehabilitation process. Researchers showed that there are many patients who have depressive disorder caused by Spinal Cord Injury. Psychological Consultants can help them and their family to decrease the depression disorder that the patient can have in the long term. .

Acceptance phase: is when a person with SCI says to himself that “It is doesn't matter! I'm a disabled person but I have to live for my family. I can turn my life around to have it meaningful !” It can take up to 1 or 2 years after the accident to reach this phase. However sometimes there are some people who can't accept this reality but also there are some persons who never can take this as a part of their life. They blame themselves to be alive, become hopeless and don't care about their future and let things come the way they are . Besides , some of them still try their best to prove that disabilities can not prevent or destroy their enthusiasm for life. Another thing that should be noticed is that loss processes happen randomly and differently on each individual according to different cases. Understanding well about loss processes will make you feel more effective and interesting in helping persons with SCI.

Discussion and questions when helping patients

The different phases of Loss Processes are : non-acceptance - negation phase, bargaining or negotiation phase, anger phase and acceptance phase.

What can doctors nurses and other health professionals do to help patients with SCI using psychological approach in those phases?

Negation phase

We should manage the negation phase softly by :

- Not putting pressure on them to accept the reality while they aren't prepared well.
- Respecting them
- Respecting their own opinion about their pathology while letting them know that you have another opinion on the subject.

Anger phase

- Helping the patient to speak out
- Listening to their feelings and anger
- Respecting them honestly

- Explaining what they are going through and will go through.

Sadness/ Depression

- Listening to them
- Helping them to change their mind
- Developing daily social communication activities
- Make the realizing the purpose of life and self-value.
- Helping their family members understand them better and how spinal cord injury acts on them.
- Helping them to restore hope and find a purpose to live
- Provide individual counselling to have recommendation for each individual person.
- If necessary using medicine for treating depression

4. General Anxiety and stress

The following disorders can occur with persons living with SCI , they are mainly confounded with anxiety that occurs after events of trauma They can be called :

Generalized anxiety (Gad) , Post anxiety (Pa), Afraid of appearing in front of people in public places (agoraphobia).

Other symptoms lie ASd and PTSD are more common with persons living with SCI.

1. Acute Stress Disorder (Asd)

It is characterized by :

- numbing or no emotion response
- not being aware of surroundings
- derealisation
- depersonalization
- an inability to recall an important aspect of the trauma

2. Post Traumatic Stress Disorder (Ptsd)

Exposed to traumatic events and left untreated

Resulted in intense fear, helplessness or horror

Distressing recollections of the event

Having nightmares, waking up shaking, etc..

Acting like the trauma is occurring

Avoidance thoughts, feelings or conversations relating to the trauma

Memory difficulties for important sequences of events

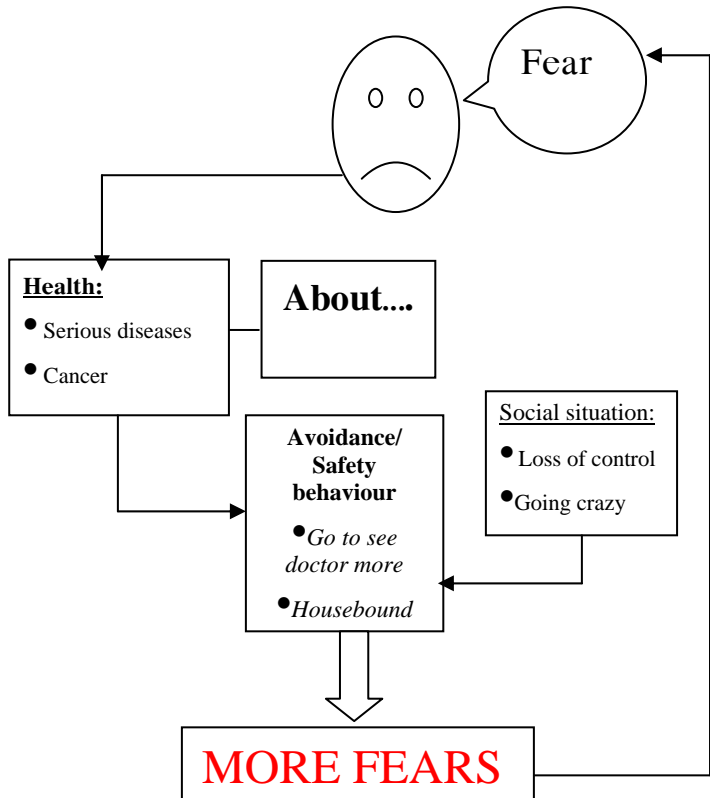
Sleeping difficulties

Angry outburst

Concentration problems

Having feelings of fear as if horrific events are occurring next to the person.

5. The cycle of fear



Fear is an important feature in the life of a person with SCI. It is a feeling the person has to deal with on a regular basis. The cycle of fear will explain the pattern better.

6. Depression

Asthenia or acquired depression is a common mental health disorder that occurs normally n to everyone. According to research of World Health Organization, there are about 340 millions people in the worlds having this disorder (WHO, 2000). Depression can happen with any category of age: elderly people, young people, adult people and children as well. Depression is one of the causes of many family problems. Fewer than 25% of those affected have access to effective treatments

The patient must has at least 5 symptoms over a 5 week period listed below. It should also impact to the daily activities of the patient:

- Feeling depressed all day
- Loss of interest in life
- Significant weight loss or weight gain (>5% of body weight a month)
- Insomnia or hypersomnia
- Psychomotor agitation
- Fatigue or loss of energy
- Feeling of worthlessness and excessive guilt
- Concentration problems, indecision
- Suicidal thoughts

7. Signs that can lead to Suicide

Taking of ones life can sometimes occur with a person living with SCI . It can be prevented by paying attention to the following signs with the patient :

- * Patient is being used to suicide before
- * Becoming addicted to liquor or drugs
- * Changing habits, feeling depressed and hopeless.
- * Undergoing of a stressful event by the patient
- * Having irremediable or chronic disease
- * Not receiving any help from family members
- * One of their family members committed suicide before
- * Unpredictable behaviour , occurrence of cruelty heavy mood changes
- * Inflicting wounds to oneself
- * A history of mental illness

8.Causes of Depression

Physical causes :

- Having illness such as cancer, stroke, chronic diseases, epilepsy, head trauma and spinal cord injury....

Relationship problems:

- Personal conflicts that couldn't be solved within a marriage or relationship
- Family conflicts (parents enforce strict education, parents overprotect the children or children were mistreated by parents)
- Loss process is too strong
- Lack of communication skills and facing hard times .
- Lack of friendliness, good relationships with people around .
- Family lacks knowledge about depression.
- Loneliness , isolation

Personal causes

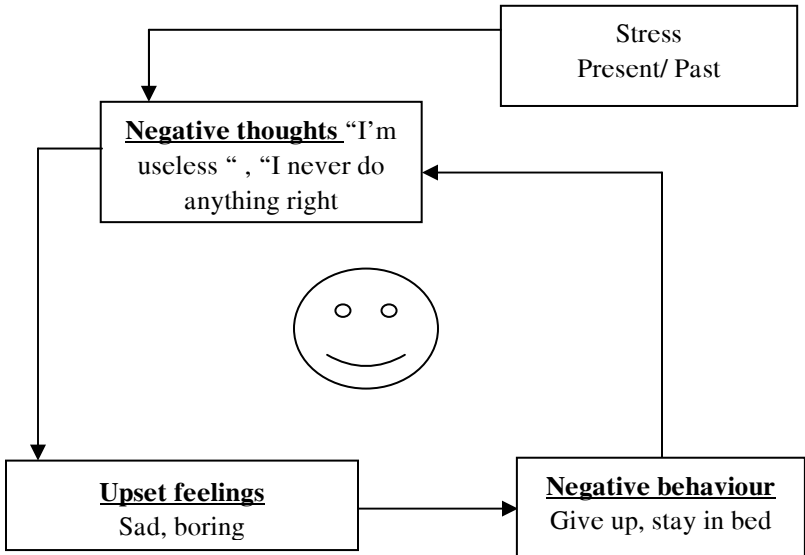
- Negative thoughts about themselves, other people and about the future
- Too much anxiety
- Conservative thoughts
- Always wants to become a “perfectionist”
- Always critical and hard to oneself

Causes of former psychological injuries and current stress

Psychological injuries such as being mistreated witnessing or being influenced by family violence.

Having seen suffering and losing one of their family members , judicial separation, divorce, leaving their children and financial difficulties.

9. Cycle of Depression



10. Treatment Options

Counselling therapy is a first step in detecting the problems occurring . Sometimes this approach needs to be matched with other strategies such as medication . In the field of SCI, the counselling step should be available as early as possible after the accident. It should be matched with an assessment that can measure the degree of severity first. This will allow a treatment strategy if needed. Medication for depression should be a last resort most of the time and be combined with counselling if possible.

a. Basic Skills of Psychological Counselling

A Friendly welcome

- Invite patient and their family members to come to a room.
- Introduce the consultant to them
- Tell them about the confidentiality and the objective of the conversation.

Starting the conversation

Ask their permission for questions not related to main problem in order to understand their background better

Ex: Could I ask you some questions about yourself and your family before going to the main subject of this conversation? How many children do you have? How about your job?

Try to express your attention on what they are saying and interest in listening to them by leaning forward, nodding your head, ask more questions if you don't understand and encourage them to talk more about themselves.

Apply usual and easy understanding words that patients are familiar with.

Create trust and go straight to subject of the conversation

- Helping them to talk about what they are concerned about.
- Helping them to concentrate on main issues that they are concerned about.
- Using appropriate words for them

Try to let them know that you are listening to them seriously by the following:

- Encouraging the patients to talk more about themselves by letting them know that you want to learn about what they are presenting.

- Asking them to explain the issues more clearly.
- Summarizing all issues that they have just mentioned
- Finding out and tell them that you are listening, understanding and experienced about:
 - ❖ Content of the conversation that you and them are talking about.
 - ❖ Their emotions
 - ❖ Try to find out what their family thinks about issues that they are concerned with (mainly parents, father, mother, grand-parents....)
 - ❖ Demonstrate that you always accept, respect them and don't criticize them.

Find out solutions that patient and their family members are trying to use to solve their own problems.

Analyse advantages and disadvantages of the solution that they are using to solve their problems, focus on their emotions that they are going through (debt, finance problems,....)

Help them to choose an appropriate solution and show them the goal of life in future.

- ❖ Using questions that can help them to have a more new and positive vision than before.
- ❖ Help patient and family members decide and plan short term and long term objectives that they can implement.

Conclusion

- ❖ Mention about subjects that you will talk with them in the next time.
- ❖ Their feelings about this conversation

Suggest questions and practical applications of important skills in psychological counselling for persons with SCI.

Asking about their emotion

When the patient talks much about what happened but didn't mention about their emotions you should ask them "What do you (Ms, Mrs, Mr...) feel at that moment?", "How about your emotion?"

Asking about what happened.

When the patient talks much about their emotion but lack of information about what happened you should ask "What happened? Or could you tell me what really happened?"

Asking about influences of event on the patient

How does the event influence to you? How will it affect you? Or how does this event influences your family (financial and emotional issues or sexuality?)

Making questions to confirm what you understood about your patients.

Did you say that....., I don't know if I understood you in the right way or not?

Keeping silent

Allow the patient to have time to think about the questions and find the answers.

Listening skill

Listening skills are one of the most essential skills that counsellor must be trained with particularly during counselling process.

Normally to understand people we have to focus on listening. Listening skills in psychology is not only listening by ears from what patients say but also observation with eyes. Listening is to feel and understand.

Listening is considered as a skill like psychological counselling. Listening is not only paying attention on what the patient said but also distinguishes separated

thoughts in the mind of a counsellor. The most important thing is to understand what the patient is trying to express but can't say in words. Observe their behaviour, their attitude, gestures, sitting position, voice, look, tears, emotion and frowns...even silence , to find out what patients try to say.

Expression skill for your listening and understanding

After listening and understanding their emotion, behaviour and the truth of the story, you can present according to what you understood, such as “ you are worried so much that you can't sleep because you weren't at home for several months and you don't know about your wife and children and your job as well, didn't you?”

Normally, if you are right the person who talks with you will express signs of agreement. If not you tell them what you understood about problems that they are facing or ask them to see if what you learnt about them is right or not? You should not try to make them believe that you understood and care about them because they showed emotions. This skill requires that you must understand them accurately.

Specific cases

In case that the patient is mumble and can't talk because he cries You should try to inquire about his

feeling, especially when you have just made a question as “ How does Spinal cord injury influence on you?”

Another case: A young lady answered your question as normal but then she started to cry and her face is full of tears. So what you are listening from this lady. These two of sample are proposed to let you think of how to apply those above skills.

Another skill is awareness of difficulties in psychological counselling process. This will help your listening effectively.

Difficulties	Example	Reaction
Judgement	“You are idiot”	Worried
Criticism	“If you didn’t drink you wouldn’t become disability person like now”	Sad and angry
Showing disrespect	“I taught you many times but you still can’t do it. What is foolish. ”	Sad, hurt, discouraged
Diagnosis	“You look like a lunatic from a mental hospital”	Feeling of not being understood.
Threat	“If you don’t do follow me you will have many problems” (problem is just a little but threat is more than that)	Worried
Asking many questions at the same time	“Why you don’t do that?, “Why?”	Feeling of being attached
Avoidance	“Should not worry too much, you will be fine”	Patient feels that they aren’t listened too and understood”
Negation	“Nothing to say”	Getting fret easily, useless feeling

b. Breaking the Bad News

Breaking the bad news to patient and their family members is a difficulty issue. It normally causes pressure for the announcer and the person who will receive the bad news as well.

Whether you want or not, breaking the bad news is part of physician job and of people who are working to help other people. Sometimes it might harm your health if you do this job on a long term.

In order to inform bad news related to Spinal Cord Injury and later complications effectively you need to have personal communication skills and psychological knowledge, especially learning about loss process. Here are practical suggestions for breaking bad news through a few main steps :

Preparation step:

- ❖ You should read patient's files carefully, especially complications of SCI and prepare yourself : “How you will explain to the patient and their family members to help them understand medical terms?”
- ❖ Prepare to manage stress that patients might have after hearing the news.

- ❖ Will the main person in their family be invited to attend the conversation?
- ❖ Who from the medical team members will be invited to attend in the meeting?
- ❖ Creating trust between physician, patient and family members is the first thing that you need to do.
- ❖ Check if the room is private, confidential or not?

Steps for Breaking the Bad News

- ❖ Ask every one to take a seat and relax
- ❖ Introduce yourself and your colleagues (if so), your specialized title slowly, moderately and confidently.
- ❖ Ask the patient and their family what they want to know about their sickness. Normally, patient they want to know about medical diagnosis in regard to their well-being and relevant complications that might happen in the future.
- ❖ Present to everyone the medical diagnosis clearly and confidently. If there are any X-ray's results or films of examination you should explain to them moderately. You should pay attention to level of education that should be different according to different people from different levels. You should not

expect that they will understand what you told them as much as you. You should repeat about their pathology many times slowly.

❖ If after breaking the bad news, no reaction is expressed, the next step for you should be to ask listeners how much they could understand and learn from what you said. You try also to evaluate where the listeners are in regard to the loss process.

Management of reactions from people who receive bad news :

❖ Attitude of being willing to listen and accept any behaviour from them will help them and their family release stress and extreme emotions because it seems they understood everything.

❖ Respect and silence is very important to them to support each other while they are in this depressed, sad and anxious process. This process should take its time.

❖ Repeat medical diagnosis and ask questions to identify how much they accept the facts.

❖ Giving answers to what patients and their family members do not understand and explain to them what you can help them with.

❖ You should take notes in assessment files to help you and your colleagues with the follow-up on breaking the bad news process to see what will be the next step

❖ You should be noticed after breaking bad news that if you feel you are influenced by this you should talk with your colleagues or somebody to release if necessary. You should not try to forget it by resorting to liquor or drugs.

Other issues when breaking bad news

1. Not going around the truth.
2. Not telling too much irrelevant information at one moment and then leaving them alone with extreme emotional shocks.
3. Listening to the patient without interruption when patient has difficulties to concentrate and to express his feelings in words because of the impact of emotion.
4. Breaking bad news is not only talking about medical diagnosis and pathology but also reinforcing trust between doctor and patient or family members to prepare effective discussions in next meetings.
5. Knowing the culture and beliefs of patients will help you predict their reactions.

C. Use of Depression, Anxiety and Stress Score (DASS)

- ❖ Used to evaluate depression, anxiety and stress
- ❖ Used to evaluate for each individual or psychotherapy program according to groups.
- ❖ Used to conduct research
- ❖ Used for health staff who are not psychologists.
- ❖ Not expensive
- ❖ Not used to evaluate patient who tend to suicide

Notices before Using DASS

- Should not be used when the patients are depressed to the point that they can't concentrate anymore.
- Should not be used when the patient has psychosis or is not aware of realities around him/her and has illusions without sound reason.
- Patient is being influenced by liquor, drugs or strong dopes.
- Time for using DASS is about 3- 10 minutes with 21 questions.

Steps in DASS's Process

Preparation

- Build up trust
- Explain to the patient main objectives of DASS” In order help you more effectively I will evaluate consequences caused after Spinal Cord Injury regarding your psychological health.”
- Choose a quiet place, private and do not be interrupted by people around you.

Evaluation process

Reading questions: “I will read following questions, please answer me if during the last seven days you had any symptom by using the following qualifuers :

- ❖ Absolutely not
- ❖ Happened Occasionally
- ❖ Happened Frequently
- ❖ Happen all the time

Then read the next question: “I feel difficulty to take a rest” then ask to qualify them. Then you keep going on until finishing all the question in the DASS table.

Then say to patient that: “Thank you for answering those questions. Hereafter I will take a few minutes to see look at the results”

Informing results

- ❖ Add all scores of each symptom then multiply by 2
- ❖ Use following table to measure results
- ❖ Influenced slightly: “You (Mr, Mrs) have slight problems about depression.”
- ❖ Influenced seriously: “you (Mr, Mrs) are very stressful after injury“
- ❖ Influenced too heavily: “You (Mr, Mrs) have many symptoms of depression. It means you have a difficult time of depression after the accident.”

Discussion for finding solution

Please notice that there are some patients who will have reactions after learning bad news from you. Your responsibility is to explain patients possible therapies, which can help them according to available services .

Take notes of all results of DASSand register into patient files.

➤ It is possible to use DASS when patient is just admitted or before discharge or according to requirement of research project.

Score	Depressed	Anxiety	Stress
Slight	12-20	8-14	18-24
Average	20-26	14-18	24-32
Serious	26-28	18-20	32-34
Too heavy	>28	>20	>34

Questions:

1. What is your experience after undergoing DASS?
2. Exchange difficulties and discuss to find out appropriate solutions

DASS 21

(Depression Anxiety Stress Scale)

Name:.....

Date:...../...../.....

<p>Please read each statement and circle a number 0,1,2, or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answer. Do not spend too much time on any statement. <u>The rating scale is as follow:</u> 0 Did not apply to me at all 1 Apply to me some degree, or some of the time 2 Applied to me to a considerable degree, or a good part of time 3 Applied to me very much, or most of the time</p>	D	A	S
01. I found it hard to wind down			—
02. I was aware of dryness of my mouth		—	
03. I couldn't seem to experience any positive feeling at all	—		
04. I experienced breathing difficulties (eg excessively rapid breathing)		—	
05. I found it difficult to work up the initiative to do things.....	—		
06. I tended over-react to situations		—	
07. I experienced trembling (eg in the hands).....		—	
08. I felt that I was using a lot of nervous energy			—
09. I was worried about situations in which I might panic and make fool of myself.....		—	
10. I felt that I have nothing to look forward to	—		
11. I found myself getting agitated			—
12. I found it difficult to relax.....			—
13. I felt down-hearted and blue	—		
14. I was intolerant on anything that kept me from getting on with what I was doing.....			—
15. I felt I was close to panic		—	
16. I was unable to become enthusiastic about anything	—		
17. I felt I wasn't worth much as a person	—		
18. I felt that I was rather touchy			—
19. I was aware of the action of my heart in the absence of physical exertion (sense of heart rate increase, heart missing a beat)		—	
20. I felt scared without any good reason		—	
21. I felt that life was meaningless.....	—		
Scores			
Sum scores for each scale and then multiply by 2			

d. Medication for treating Depression

According to the symptoms as below:

Symptoms	SSRIs	SNRIs (Efex-)	RIMAs (Auro- rix)	NaSSAs (Avan- za)	NARIs (Edro- nax)	TCAs (Tryp- tanol)
Depressed	vv	vvv	v	vv	vvv	vvv
Insomniac	-	-	-	vvv	-	vv
Stress/ fear	v	v	-	vv	-	vv
Fatigue/Loss of energy	-	-	vv	-	v	-
Headache	-	-	-	v	-	vv
Pain	-	-	-	-	-	vv
Anxiety/ horror	vv	v	-	-	-	V
Obsessive compulsive disorder	vv	v	-	-	-	vv

Source: www.beyondblus.com.au (2004)

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