



YOUR BAGGAGE

– assessing your needs

You might know of the pain scale, where you are asked to describe your degree of pain on a scale from zero to ten. Anything above five indicates significant pain. Just like with the pain scale you can use the checklist, see next page, to specify the extent of stress or strain you feel on a scale from zero to ten, on both physical, mental, social, and existential challenges. You can fill out the checklist while you wait for a treatment or meeting with your doctor, and it then forms the basis of your “Travel Itinerary”.

When you are using the checklist you are asked to estimate the degree of stress/strain you have experienced during the past week. The scale ranges from “no stress/strain” (zero) to “extreme stress/strain” (ten). A higher value might be a signal that you need some form of professional help. See the scale only as a simple guide where your own feelings and your own assessments of which support and help you need are the most important.

To help you with this, there is a list of areas where you can feel stress/strain, a list of problems others are faced with, and a list of available support. Please select the problem you have noticed during the past week and what kind of support you think you need. If you are missing an alternative you can write it down on an empty line.

The purpose of the checklist is to help you and your treatment team to draw attention to your needs for support and treatment. Simply put: your rehabilitation needs! If you want to use the checklist several times it is available at www.thecancerjourney.se.

What specific problem/problems have contributed to an increase in stress and strain in the past two weeks?

Breathing
Work
Troubles with balance
Childcare
Decisions about treatment
Accommodation
Depression
Diarrhea
Finances
Loneliness
Fever
Constipation
Hygiene
Health problems in the family
Identity/who am I?
Nausea
Anger
Itching
Concentration
Feeling bloated/swollen
Digestion
Weakness
Meaning and context
Memory
Addictions
Mouth sores
Muscle weakness
Possibility of having kids
Sadness

Put an X on the specific problems that feel relevant.

Nervousness
Stamina
Problems urinating
Relation to children or family
Relation to partner
Fear
Mobility
Sexual problems
Healthcare insurance
Pain
Language and speech
Tingling in hands and feet
Studies
Troubles swallowing
Sleeping
Thoughts about death
Lost interest and desire
Dry skin
Dry mucous membranes
Transportation
Fatigue
Appearance
Troubles eating
Other problem:
Other problem:

Put an X next to the color that describes you best. Mark how you are feeling with the help of the colors below. Red is high stress/strain and green is low.



Put an X on the specific problems that feel relevant.

Within which area/areas do you experience an increased stress and strain now?

Existential challenges
Physical challenges
Social challenges
Challenges related to sex and intimacy
Physical challenges

Based on the stress and strain I experience I think that I would need to get in contact with the following people:

Occupational therapist
Dietician
Counselor
Speech therapist
Doctor
Support person (organization/association)
Psychiatrist

Psychologist
Sexologist
Physiotherapist
Nurse
Spiritual counselor
Other contact:



TOGETHER WE CAN MAKE THE CANCER JOURNEY MORE EASILY NAVIGATED

– www.thecancerjourney.se

During our work with “The involuntary traveller” we have encountered the commitment and ingenuity of those affected by cancer. That also led to thoughts regarding what genuine patient and significant others’ influence is about:

As a person affected by cancer you are a specialist in yourself and the needs you have. You also have the “travellers” perspective and thus a unique competence for what can improve the journey that those affected by cancer must undertake. It really should be you who tell healthcare and society how things should be and function. At the same time, it is our experience that this is rarely the case, and that this competence is not properly harnessed within research, healthcare development and societal planning.

Together we can change that!

We believe that there is an abundance of good ideas “out there” – ideas that can shape projects – projects that can make the cancer journey more easily navigated for everyone involved. “The involuntary traveller” is the beginning of a project to actively harness your, and others affected by cancer, experiences, ideas and commitment.

The website www.thecancerjourney.se constitutes the bud of this project and there you can:

- Find forms and other material pertaining to the book.
- Reconnect with what you think about the book, good and bad, and discuss and give suggestions for support, services and functions.
- Support and participate in projects that is pushing development of the cancer journey from the perspective of those affected by cancer.

We warmly welcome you to influence and work together with us!