



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?

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

Put an X on the specific problems that feel relevant.

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

<input type="checkbox"/>	Existential challenges
<input type="checkbox"/>	Physical challenges
<input type="checkbox"/>	Social challenges
<input type="checkbox"/>	Challenges related to sex and intimacy
<input type="checkbox"/>	Physical challenges

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

<input type="checkbox"/>	Occupational therapist
<input type="checkbox"/>	Dietician
<input type="checkbox"/>	Counselor
<input type="checkbox"/>	Speech therapist
<input type="checkbox"/>	Doctor
<input type="checkbox"/>	Support person (organization/association)
<input type="checkbox"/>	Psychiatrist

<input type="checkbox"/>	Psychologist
<input type="checkbox"/>	Sexologist
<input type="checkbox"/>	Physiotherapist
<input type="checkbox"/>	Nurse
<input type="checkbox"/>	Spiritual counselor
<input type="checkbox"/>	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!