



Quality of Life – Vision Document

The mission of Inspire2Live is:

Get cancer under control and inspire people to lead Happy and Healthy lives in Harmony with cancer.

We achieve this by motivating as many people as possible to constantly challenge and expand their boundaries.

Inspire2Live has the following themes:

- Quality of Life
- Reducing incidents
- Quality of Care
- Innovation of the Clinical Practice
- Understanding Life (the Inspire2Live program to get cancer under control)

Quality of Life

Quality of Life is that which each patient aspires to, but there is only one person who knows what it is, experiences it and lives it: the patient him/herself. Quality of Life has to do with your own sense of well-being and it is precisely because this is different for all and changes during the care process, that it is important to be well informed and to talk about the issue. Not only you as the patient but also those around you with you.

The unrelenting reality has stories of the 'clumsy' doctor, the harrowing stories of employers and colleagues, physical inconveniences, fears and uncertainties, a childhood dream which can no longer be fulfilled, stresses and strains in relationships and also the patients who have trouble in determining and/or indicating what fits and does not fit in their changing lives.

Purpose of the Quality of life theme

The Purpose of Quality of Life is to:

- Facilitate and inspire the patient and his/her loved ones in achieving a happy and healthy life in harmony with cancer by offering practical tools, which help to raise awareness of choices so that the patient can maintain control
- Place the patient as an individual centrally in all interactions that occur during and after a treatment for cancer by entering into a dialogue with the relevant organizations over the current practice, with the aim of making improvement proposals and participating in their realization. In addition to healthcare providers, this includes, for example, insurers, employers, policy- and opinion makers, scientists and pharmaceutical companies.

Quality of Life Topics:

- (a) Cancer and physical, psychological and social balance
- (b) Cancer and social position - work, insurance
- (c) Cancer and lifestyle
- (d) Cancer and obtaining relevant information about your disease and treatments
- (e) Cancer and obtaining the care, treatment/medication that fits your situation.

On (a) physical, psychological and social balance

Understanding and acceptance by, and for, the cancer patient and those around him/her, as a result of the life changing diagnose. Both attention for the patient him/herself as well as those close to him/her, for example, about

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purpose and meaning in life, help in dealing with uncertainties, physical inconveniences, care for children, attention to relationships which may be under pressure, the choices in the care process, etc.

On (b) Social position

Fully and realistic approach to return to society. Subjects are for example; I am a colleague with possible restrictions to be taken into account; What are your rights and obligations? What can the employer and colleagues take into account? Patients also have access to insurance and mortgages, especially if cancer is no longer a deadly disease.

Ad c) Lifestyle – See *Reducing incidents*

A healthy lifestyle can help to prevent cancer, a positive contribution in the fight against cancer and/or increase the feeling of well-being; movement, nutrition, obesity, stimulants (such as alcohol, smoking, sunbathing).

On (d) Up-to-date information about your disease and treatments – see also *Quality of Care*

We are talking about fundamental decisions and it essential to be well informed and to be able to go into subject matter in depth. Examples are: clear information on effects and side effects of disease and treatment ((im-) possibilities and the risks which have an impact on the quality of your life), access to own medical files, what will happen and when, which support channels are there (home care, patient groups, psychologist), trials, etc. Which hospital specializes in my type of cancer, doctors will respect your choice of, and/or stopping or not starting a treatment.

On (e) Obtain care, diagnosis, treatment and medicines, which fit in your situation – see also *Quality of Care and Innovation of the Clinical Practice*

Doctors put their patients first, keep abreast of the cutting edge of knowledge and act responsibly.

After the information and decision-making the patient gets the corresponding best possible treatment in specialized cancer centers. The wish of the patient is more central, regulations and protocols are no longer be sacrosanct, individualized medicine/approach, no under or overtreatment. New techniques (diagnostics, proton radiation therapy, the right medicines available in the right way, faster access to new medicines, participation in trials, operations without incisions) with sufficient capacity which is accessible equally to everyone. Extension of the basic insurance package with new promising cancer treatments, scan and scan results within 1 day, more research into cancer and treatments for cancer at a young age and for rare cancers.

In the area of Quality of Life there is a lot to be gained for cancer patients. The Patient Advocates of Inspire2live are fighting for these gains.

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