

Late consequences of cancer: what are your experiences?

The Dutch Federation of cancer patients (the [NFK](#), [Nederlandse Federatie van Kankerpatiëntenorganisaties](#)) asked this question in October 2017 to 3679 (former) cancer patients.

What are late consequences?

By 'late consequences' we mean long-term changes that they experience on a psychological, physical, cognitive level that are limiting your daily functioning.

You can think of, for example: fatigue, concentration problems, sexual problems, fear of cancer recurrence, depression, not being able to perform your work properly, neuropathy or cardiovascular diseases. Sometimes it is not certain whether certain complaints are a result of (the treatment of) cancer or something else (for example, getting older).

'Only when the treatment was finished I became aware of the consequences of cancer on my life. I was completely overwhelmed by that and I noticed that your environment also experiences this. Now, a year later, I am still processing the experience and it's impact on my life. The external opinion is that I look 'healthy' again, but inside there is still a lot to heal. That does not understand everyone and sometimes produces uncomfortable situations. Nevertheless, it goes the step by step the pleasant way. '

Due to the 'late consequences' that you experience, you may encounter misunderstandings from the environment: 'You are out?'. Well-intentioned, but sometimes also painful remarks that many (former) cancer patients get.

Who completed the questionnaire?

The 3679 (former) cancer patients completed a questionnaire. Average age was 60 years and 62% were women. Breast cancer (62%), prostate cancer (19%) and colon cancer (14%) were the most common types of cancer.

The outcomes

To what extent do (ex-) cancer patients experience 'late consequences'?

The results show that 24% of the (former) cancer patients who completed the questionnaire have never heard of 'late consequences' of (the treatment of) cancer. A majority of 65% indicate that they experience 'late consequences' themselves. And 20% indicate that they have complaints, but do not know if this is cancer-related.

The most common 'late consequences'

1. Fatigue (68%)
2. Reduced physical condition (54%)
3. Sexual problems (44%)

4. Concentration problems (40%)

5. Memory problems (37%)

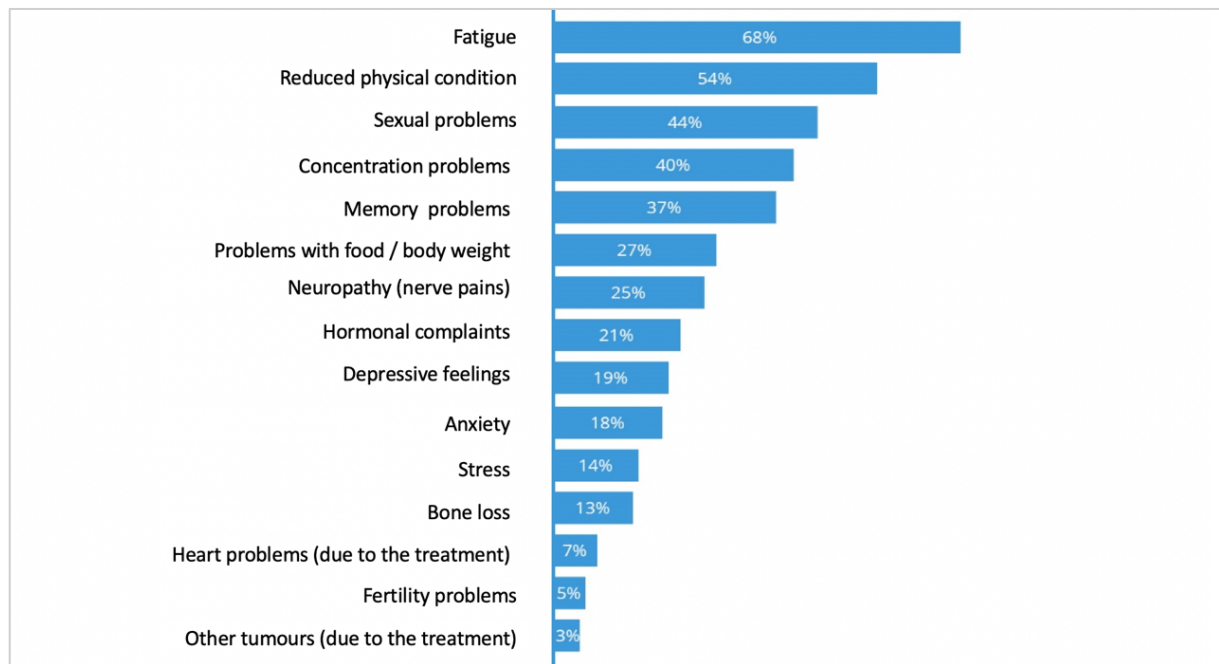


Figure 1. Experienced 'late consequences' by (former) cancer patients.

Women vs men

Women experience 'late consequences' a lot more often than men. This applies to all problems and complaints mentioned in figure 1, with the exception of sexual problems. Men experience sexual problems more often than women.

Young people versus the elderly

The results show an effect of age: younger (former) cancer patients more often experience 'late consequences' than older ones. This applies again to all problems and complaints mentioned in figure 1, with the exception of sexual problems. There we see that people of 65 years or older experience significantly more sexual problems.

Time since diagnosis

As time passes after a cancer diagnosis, fewer 'late consequences' are often experienced by (former) cancer patients. This applies to all problems and complaints in figure 1, except for bone loss and heart problems. These are more experienced by the group of people who received a diagnosis five years or longer ago. No differences were found in fertility problems and second tumours.

How do (former) cancer patients deal with the 'late consequences' of cancer?

People deal with the (late) consequences of cancer in different ways. Most people (73%) talk to their relatives, such as their partner, family, friends, about the 'late consequences' they experience through the (treatment of) cancer. A large majority (56%) also does sports or physical activity. In addition, 55% of (former) cancer patients try to prevent overload by adjusting their activities. Other ways of dealing with 'late consequences' are shown in Figure 2.

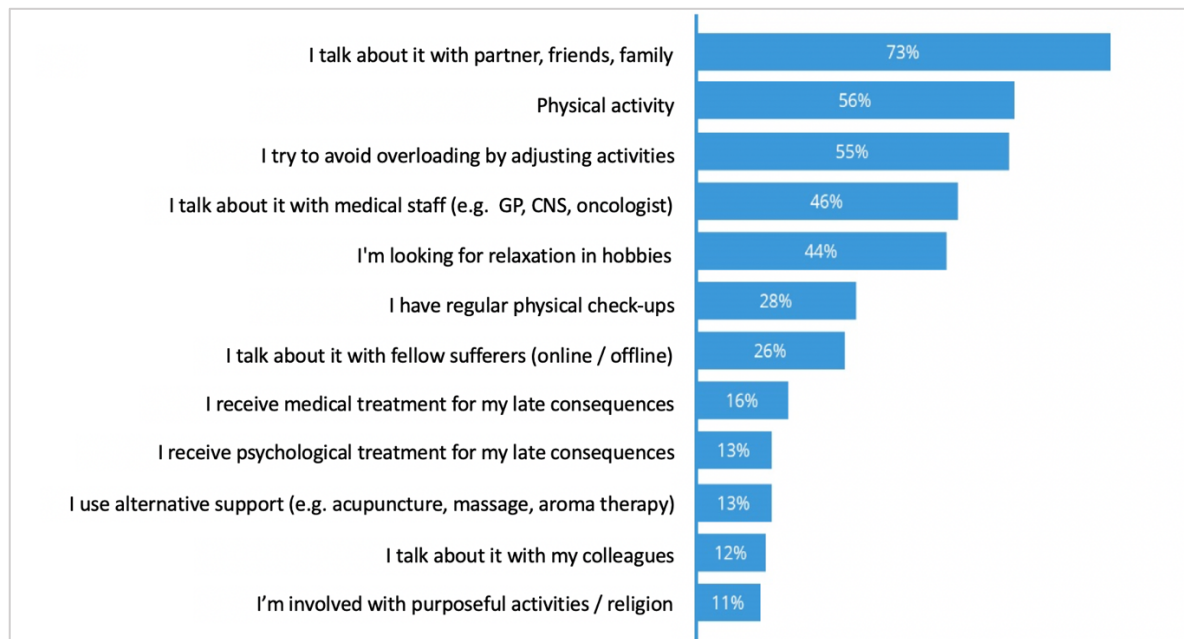


Figure 2. Ways that (former) cancer patients deal with late consequences

To what extent is the daily life of (former) cancer patients limited by the 'late consequences' of cancer?

(Former) cancer patients indicate that they are particularly affected in terms of hobby and sport, and work and school due to the 'late consequences' of cancer (see Figure 3).

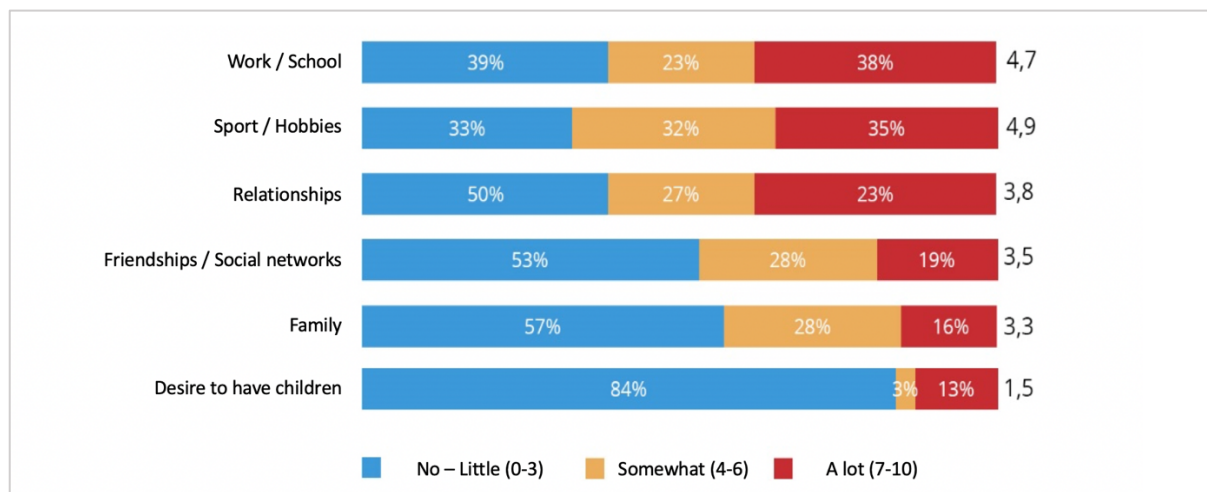


Figure 3. Degree of limitation on daily life: 0 = not at all limited to 10 = very limited

To what extent does the environment show understanding for the 'late consequences' of cancer?

In general, (former) cancer patients experience a lot of understanding of their environment (see Figure 4). In particular, their partner, family, family and health care providers in the hospital.

Remarkably, on the other hand, there is clearly less understanding at work of colleagues, managers and employers.

'At work we are in the middle of a major reorganisation, if I give in on work then I will not survive the reorganisation. This is at the expense of my income and I depend on it. '

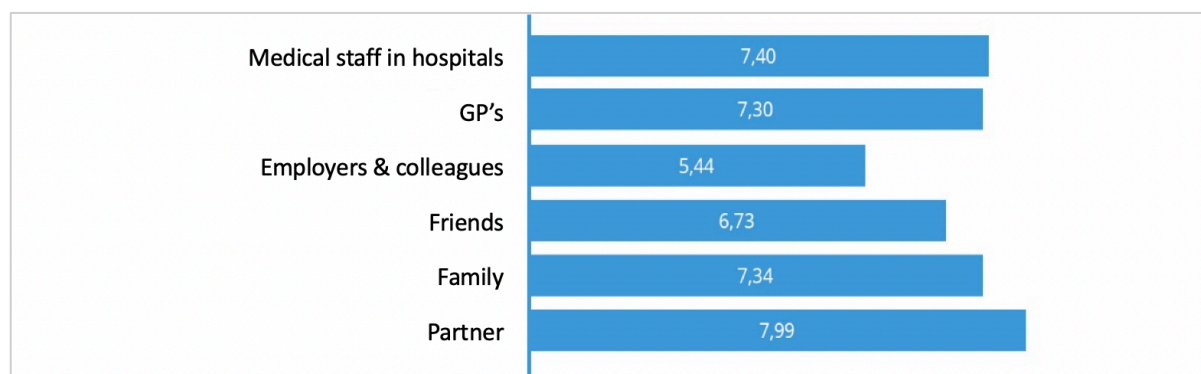


Figure 4. Degree of understanding of the environment: score 0 = no understanding at all - 10 = very much understanding

Conclusion

We conclude that the majority of (former) cancer patients suffer from 'late consequences', these are diverse in nature. It is important that both caregivers and patients are aware of the chance of 'late consequences', so that problems are identified in time and where necessary refer to specialized care.

Striking are the results in terms of work. (Former) cancer patients feel limited at work due to the 'late consequences'. Also, little understanding is experienced from the work. Employers should be alert to this. More information about 'late consequences' at work can be found at Kankerenwerk.nl (Dutch website).

'Listen to your own body and try to find a good balance for yourself. This will take time. Also try to have some understanding for your loved ones, they also need to learn how to deal with the changed situation. It is often difficult for them to understand what impact cancer has directly and indirectly. Talking to your loved ones is very important even though it is sometimes quite difficult. It often helps and there is a chance of more understanding on both sides. '

Actions

[NFK](#) and other cancer patient organisations will start a campaign to draw attention to the 'late consequences' of cancer and its influence.

The target groups are patients, caregivers, general public and employers / HR. This will happen as an online campaign with articles and a targeted action to employers and HR. The results will also be used for a national knowledge agenda of the Cancer Survival Task Force.