



## One way, many paces – unique inspiration to win over the disease

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One question rises up in everyone's mind when they are faced with the fact of suffering from a chronic disease. Every day many patients in the world gain the knowledge of a hard fact that their life will change dramatically. The realization could seem terrible. According to the Kübler-Ross model, the well-known common phases of terminal illness are denial, anger, bargaining, depression, acceptance.

This model is a very reliable scheme of the phases during the process of accepting a terminal disease. Usually none of these phases is missing in this process.

- We experienced in a particular case that in order to reach the last phase of this development, the best method could be social activity. We wondered what kind of general rules and suggestions we can make to help patients in any kind of terminal illnesses to find an aim which they could realize. Due to the development of medical science more and more patients with incurable but treatable disease get the opportunity to live a nearly full life.
- We think these basic principles could be useful in any case of other terminal diseases as well, not only in end-stage renal disease.
- In the recent years, leisure and sporting activities have received more significance in the rehabilitation of patients as we recognized that besides the general feeling of the patients, it can improve their medical condition and results.

This study was based on a challenge set out by a patient diagnosed with end-stage renal disease. A 41 years old patient decided to gather together hundreds of patients with end-stage renal disease each year. The aim was to create an opportunity for them to continue their favourite activities: biking and social life. First of all the most important step is to consider the disease as an opportunity not hardship. More than 140 patients attended the 220 km bike tour as a result of two years of effort including advertising, collecting of information, getting in touch with several patients and arranging medical care for them. We were interested in what could be main features of organizing such a big event.



Interested in the main motivations of organizing such a big movement, we asked the organizers:

*„The bike tour that we started a few years ago highlighted some things that were not considered as important as they should have been. For example losing empathy among the ill and even the healthy. This event carefully brings the ill back into a group, and parallel to this process the patient gets back in the social activity, and realizes that despite the disease their former leisure activity could be continued. This is a very important realization in order to accept their situation and even to see the advantages of the changes of life.”*

We assessed how many people could be controlled in an appropriate way to make such an event successful. As the main organizer of the tour said:

*„It doesn't matter how many people would like to attend the tour: 10 or 300, because smaller groups will shape within the whole company which help each other. It's very important not forget about the children! Contrary to what we believe, children are more controllable and they are much easier to cooperate with than adults! I would like to underline not to forget the children, not to be afraid of working with them to reach such an aim.”*

What could be the advantages of a collaboration between a volunteer helping movement and professional helpers?

*„This movement was originally founded for the patients and for a few medical specialists who can help us. But to our surprise, we experienced a bigger interest and attendance from the professional helpers. We realized that no one takes care about their problems in the treatment process, but they need this.. Some patients can cause very hard moments in their work.”*

### We found 3 main advantages during our study:

1. Possibility to go on with the original favourite activity,
2. Getting in touch with other patients from distant centers,
3. Such community activities can provide a lot of extra information for the patients living with end-stage disease and for the medical staff.

We examined the best method for organizing and coordinating such a big event to create a useful scheme. In accordance with the experience of the former years, the sporting activity and the continuing of former leisure activities became more and more important regarding the acceptance of chronic disease and the changes of life.