

Annales Universitatis Paedagogicae Cracoviensis

Studia ad Didacticam Biologiae Pertinentia III (2013)

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Bien vivre avec sa maladie

New book recommendation



The disease comes at us like a bolt from the blue. And when it is very serious (cancer of the breast or prostate, stroke, kidney failure...) or chronic (diabetes, asthma, obesity, heart disease, cardiovascular disease, rheumatoid arthritis, chronic back pain, etc...) it crushes us completely. We are in depression or we despair, we think that everything is “damned”... then comes a psychological shock, a revolt, depression, and moreover – physiological disturbances.

Few people are prepared to face it. It is true that the topic of disease does not have its place in school, even health is not very important in the curricula. The body itself is taught in installments as a separate glossary devices; despair that many students. But over a lifetime, are often those who can escape... Currently, a quarter of Europeans (150 million) are suffering from a disease of long duration.

It happens often by surprise, then comes the doubt and complaining. Is it possible to prepare for this? Accepting the disease is difficult, long-term illness is a daily treatments, the need for lifestyle changes and lack of acceptance of self.

Yet the person called “sick” can learn to live “healthy” with their illness... and it can surely prevent some complications. And in certain diseases, type 2 diabetes,

obesity, back pain or heart disease, it may even lead to certain remission, if changes are introduced in behaviour or lifestyle.

Learning about the disease

What good is it to know or understand one's disease treatment? Can we not fully trust our doctors, and their medication? "He's an expert", "it is he who knows"... It is not so simple! Everything depends not only on the caregiver. When you are suffering from a disease that medicine calls "diabetes", for example, you must understand why sugar is "high or low" in the blood. You must take care of what you eat. A person with this disease is always in a "crossfire" of "too much sugar" or "too little".

But who knows about their health, the means to preserve it or recover it? So what does it take to heal? And what about the drug treatment? What are the side effects? Can we avoid them? What kind of knowledge is necessary?

However, it was found that when a person suffers from a disease and especially its treatment, it is better to monitor it and reduce complications. For diabetes, the numbers have been reduced by 80% for amputations and 90% for the risk of blindness. Similarly, asthma attacks or relapses in cardiovascular disease were reduced by 80%. Moreover, most of the risk factors for cardiovascular diseases are preventable, being directly related to lifestyle.

Regain your autonomy

Know more, the patient can find self-efficacy, and even regain their autonomy... By informing and forming gradually, they can acquire the knowledge and skills to best prepare a balance between the ideal control of their illness and their daily life.

When patients know better, they are also less dependent on their caregivers, and they can make better choices. Some people may even become "co-therapists" by shaping behaviors that are the best for them to solve health problems. The patients become the real "authors" of their health, the "owners" of their body and the treatment.

They can ask the right questions, consult the best experts and identify what suits them best. Permanently, they can interact with caregivers in making decisions about their health. Do not forget that such persons live permanently with their illness, while the doctor is interested in it for 20 minutes from time to time... in this way, the person suffering from a disease, even a serious one, learns to anticipate and react quickly to a crisis. Patients avoid a new behaviour worsening the situation, or prevent suffering from a relapse; such treatment may even go into a form of healing.

Grow by illness

The behavior of a sick person is an important factor in treatment and care. What would they change? Some patients were asked questions about their way of life. Do

we not have a pathogenic behaviour? An unbalanced diet, for example? Or too much stress? Change the diet, undertake physical activity, avoid addictions to tobacco and alcohol: these basic tips should be included on the prescription before medication.

There are even people with the disease that could “grow”... The management of their condition has led them to ask questions about their values and the link between their values and their lives. Others have had to make drastic changes in their lifestyle choices, they upset their habits, they brought moments of sharing and created associations or sites to support people in greatest difficulty. They could then be fulfilled otherwise than they had been before, caught up in the daily routine. They became “otherwise”...

Do not expect everything from caregivers or medicaments. Notably, bring meaning to what you experience. To begin with, accept what you are to change “a little”, gradually. Clarify your values, repérons those who really take you to “heart” and live as much as possible according to them. Making the link with others is often a way to find meaning, and, first of all, to link with yourself.

Do not expect everything from the outside, we have a lot in our own hands... Take advantage of the knowledge or accompaniments that caregivers can bring us. But look within yourself for a life that corresponds to what life you want to lead...

For more

A. Giordan et A. Golay, *Bien vivre avec sa maladie*, Lattès, 2013

Professor André Giordan, a physiologist and epistemologist, founded the famous Laboratory Didactics and Epistemology of Science at the University of Geneva. Well known for his work on learning, the complexity and changes, he is a consultant in patient education.

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