

**Program Script for Alper Kaya (Aired on 06 December 2009)**

**Category:** Civic Participation

**Location:** Izmir

The love between the day and the night is very similar to the love between the rain and the land. They always reunite with each other.

That’s life. The world keeps turning and you believe that you will live forever healthily.

Things may go in a different direction, however. A small illness that you consider to be insignificant can change the rest of your life.

This was how Dr. Alper Kaya’s life was transformed.

Alper Kaya, an eye doctor, would wake up every morning to walk to the hospital he worked for. One morning, he felt an indescribable pain in his groin.

He did not make a big deal out of it at first, but as the pain did not go away for a while, he had to go see a doctor. And after many consultations, he found out that he was diagnosed with ALS, a disease he never heard of before.

That moment, he realized that his life will never be the same. It was very hard to accept this fact. Until that moment, the only thing that he could think about was his wife who was pregnant to their first child. But now, he started to also think about his own disease.

Once he started having difficulties breathing, doctors recommended him to use a breathing device. They opened a hole in his throat and his artificial respiration started. The noise that this device makes became the melody of his life for the last 20 years.

You will also hear the noise of this device in the background for 20 minutes during this episode. Please remember that he has been living with that noise for 20 years.

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**Interview with Alper Kaya:**

**Alper Kaya:** “ALS is encountered in 2 to 6 people out of 100,000. It is a disease caused by the malfunction of motor neurons. As the neural system is malfunctioning, the metabolism cannot produce sufficient energy to move your muscles. Consequently, muscles become weaker in a gradual manner.

You lose your moving ability, but your mental functions such as your judgement, perception, and thinking do not get affected at all.”

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Alper Kaya’s life completely changed after being diagnosed with an incurable disease called ALS as a 28 year-old doctor. First he had to quit his job at the hospital and then he had to wait for the disease to take over his life.

He was faced with a decision during those depressive days. He had two options to choose from and these options were different from each other as black and white.

He was either going to pick black and give up on life. Or he was going to pick white and start a remarkable journey of struggle for himself and others like him.

Alper Kaya picked the white option.

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### **Interview with Alper Kaya:**

**Alper Kaya:** “I realized as a doctor that I was going to die in 5 years. This is one of the hardest things to swallow for a human being. Your life is coming to an end. This leads the patient to a severe depression. It is a time to decide if you will give up or keep on going. According to their beliefs and/or personalities, some people hold on to life and some give up on it.

I had a very personal reason to hold on to life; my wife and I had a baby right after I was diagnosed.”

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When he was diagnosed with this very rare disease encountered in 1 out of 50,000 people, the person who was closest to him, his wife was the first to show her support. She told him that they were going to give birth and that they were going to raise the baby together.

With the support of his wife, Alper Kaya started looking for ways to live with that disease instead of avoiding it. He started to combine his medical knowledge with experiences he gained from living with ALS.

Meanwhile, the disease started to take over his body.

He first lost his ability to walk and then his hands lost their functionality. Once he started his new life, first thing he tried was not to lose contact with the rest of the world.

He could still use a computer as much as the bit of senses he has left in his hands would allow him to.

He translated and adapted a program developed in Germany to Turkish, in order to help his computer usage.

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**Interview with Alper Kaya:**

**Alper Kaya:** “I thought that I would be unable to use a computer if I was not able to type on a keyboard. After doing some research, I found out that there was a solution for that also. One of these solutions was the “cyber keyboard”. Although not much, I still can move my hands as you can see. But I cannot move the cursor from one corner of the screen to the other. Therefore, I changed the mouse sensitivity settings to the most sensitive level. Thereby, I can move the cursor with small hand movements. I can do most of my work on my computer thanks to a program we developed together with Tom Weber, a German friend of mine whose mother was an ALS patient also.”

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As his computer and the internet connected him to the rest of the world, he decided to share his motivation and knowledge with other patients.

He sent emails to and called ALS patients from all across Turkey. He became a doctor and a friend for other ALS patients and their relatives who were feeling lonely and isolated.

He gave them his contact information and told them to call him whenever they wanted to.

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**Interview with Alper Kaya:**

**Alper Kaya:** “We have a forum on our association’s website. I receive numerous questions from there. I read them one by one, group them and try to answer to all questions in one general message. I can talk on the phone. What else can one ask for?”

I try to gather all information I can learn from my friends in order to share them with other ALS patients. I question the applicability of methods implemented in different countries by communicating with people from all across the world through sending out emails and making phone calls. And I try to share the information I gather with ALS patients in Turkey as much as I can, so that they can implement these methods also.”

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Alper Kaya does not only support ALS patients through the phone and the internet. He organizes fundraising campaigns for patients who do not have battery-operated wheelchairs or sickbeds and involves volunteers to provide patients with supplies they need. He makes a difference in the lives of hundreds of ALS patients.

The way that ALS shows its signs and progresses from one metabolism to the other. ALS is known in the world as the famous physicist Stephen Hawking’s disease. While the disease progresses very quickly in some metabolisms, in some cases it ceases to progress after a certain point.

Umit Dogan was diagnosed with ALS very recently. A factory worker until 2 years ago, he now has to live at home with the help of his battery-operated wheelchair.

He did not even have that battery-operated wheelchair until 6 months ago. He was dependent on other people’s assistance and could not leave his room.

Alper Kaya started a fundraising campaign for him on the internet 6 months ago. With the help of donations, he now has a battery-operated wheelchair, or his freedom in his own words.

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### **Interview with Umit Dogan:**

**Umit Dogan:** I did not know anyone before getting this wheelchair. Ms. Saadet added me on Facebook one day. I met Mr. Nuh thanks to her. Then we went to see Dr. Alper Kaya together. He told me that I need a battery-operated wheelchair. Because for a year and a half, I lived in this room. I received my battery-operated wheelchair recently, thanks to the campaign initiated by Alper Kaya. I want to thank everyone who supported me.

**Interviewer:** I guess your life changed a lot, didn’t it?

**Ümit:** Yes of course. Now I am just like you, besides the fact that I cannot walk. But I am very grateful.

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Nuh Evren is suffering from one of the most severe levels of ALS. He started with having breathing problems 1,5 years ago and today he can only move his eyebrows.

The rest of this body is connected to devices. Despite, Nuh Evren and his 17 year-old son Beycan developed a communication method where Beycan talks and Nuh Evren moves his eyebrows.

Just like in the movie “The Sea Inside” by Alejandro Amenabar, they are swimming in an infinite sea together.

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### **Interview with Beycan Evren:**

**Beycan:** We developed this method ourselves as we had a hard time communication after the diagnosis. We divided the alphabet into 5 rows and my father uses his eyebrows to communicate.

We would put together the letters in order to form words. For example “a,b,c” is on the first row and “e,f,g” are on the second. I would start counting row numbers and he would blink at the row where the letter he wanted is situated. That’s how we form words to communicate.

We talk to Dr. Alper Kaya on the phone and through the internet. He tries to helps us out when we are in need. He knows some doctors who can help us when we encounter a problem in a hospital. That’s how he supports us.

We encountered many problems with ambulances. Not so much when going to the hospital, but they would cause some problems when transporting us back home. They would not carry my father upstairs to our apartment. We asked Alper Kaya what we could do about this. This issue became so severe that we had to write a letter of complaint. Because they would not carry my father upstairs.

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Alper Kaya showed his support to other patients on the internet, on the phone and by fundraising campaigns he organized. His efforts inspired many new ALS volunteers in Izmir.

Alper Kaya helped Hakan Sepici as her mother was an ALS patient. Today, although his mother is passed away, Hakan Sepici is trying to help out other ALS patients on a voluntary basis. He lends a hand to patients along with Alper Kaya.

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### **Interview with Hakan Sepici:**

**Hakan Sepici:** “We try to provide our patients with financial assistance, wheelchairs and breathing devices. We are cooperating with the ALS Motor Neuron Diseases (ALS/MND) Association. Patients’ needs differ in each phase of the disease. They need to exercise, they need moral support...We try to bring our patients together, we make visits with groups of two or more people.”

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Dr. Alper Kaya has been an ALS patient for the last 20 years. He is always in contact with the ALS/MND Association, located in Istanbul. He is not at war with his disease, he learnt how to live with it.

He shares all his knowledge and experience with people in need. He acts as a source of motivation and strength for other patients. Meanwhile, he never overlooks the support of his wife.

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### **Interview with Alper Kaya:**

**Alper Kaya:** “Such things make us feel that life is good after all. If you lead a very slow life, you have more time in your hand to get to know people around you in a more detailed way.

As days go on, I get the chance to get to know my “Iron Lady” better and better. I get to feel the beauty and the strength in her soul. That’s the reason I call her my “Iron Lady”.

Our friends know this already, but I’ll say it again: She’s my Iron Lady!”

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**Alper Kaya never gave up on life since the first day he was diagnosed. He worked in pursuit of a better future not only for himself, but also for other people around him.**

**He contributed to the lives of people he never met before. He encouraged other people who are ALS patients just like him.**

**Instead of being weary of life, he embraced it. And he made a remarkable difference in the lives of hundreds of people.**