

Sue Clarke on the loss of her brother David

He said, “I want to become a tree.”

David is 44 years old when he is diagnosed with ALS. The fatal nervous system disease forces the professional golfer into a wheelchair within weeks, crippling his body and depriving him of speech. They felt like they were on a roller coaster, says Sue Clarke, who was at her brother’s side. David Clarke is 47 years old when he passes away.

Interview: ALS Association Switzerland, Thomas Stucki

ALS is known as “the disease of 1,000 farewells”. It is incurable and fatal, generally leading to death within a few years. As a relative, did you have the chance to realize what was happening – to notice how your brother’s illness was affecting you as well?

No – and I didn’t even want to think about it too much. That would have been dangerous. I mean, you have to just go on. Of course you re-

alize that it’s having a massive impact on your own life. But what else could I do? If I had thought about how I was doing, I would have felt com-

pletely overwhelmed. You can’t do that in this kind of situation.

On your Facebook page, you quoted Winston Churchill: “It is a mistake to try to look too far ahead. The chain of destiny can only be grasped one link at a time.” How do you cope with the fact that your brother died of ALS within three years?

I still haven’t wrapped my head around it. You simply try not to look too far ahead. Everything happened so fast – every problem we overcame was immediately followed by the next one. Then we had to think about what to do: was there any help, would we get support, what do we need financially?

It was a roller coaster that we couldn’t get off. We always had to look ahead, but not too far ahead. At the back of our minds, we all thought, my God, it’s happening so quickly. David knew it, too, but he didn’t want to believe it. But that was also the source of his strength. He had an enormous will to live and fought hard. All the way to the end.



Sue Clarke and her brother David (Courtesy: Sue Clarke)

ALS can lead to changes in personality. Did you notice that with your brother?

The doctors had told us that something like that could happen (comment: frontotemporal dementia with symptoms like changes in social behavior, problems recognizing emotions, loss of ability to understand the illness). But my brother didn’t change as a result of the disease.

Unstoppable attack on the body

Amyotrophic lateral sclerosis (ALS) is an incurable and fatal degenerative disease of the central and peripheral nervous system. After sufferers first experience symptoms, they generally have three to five years left to live. The illness stiffens and paralyzes the body’s musculature. While ALS affects different people in different ways, it usually leads to rapid and significant restriction for the affected person.

How did your brother react to the diagnosis?

When I was with him on the first day after his diagnosis, we were still in shock. Even though he had suspected what it might be, it's another thing altogether to have the diagnosis. To see in black and white that it's ALS. Shortly afterward he said, "Now I'm going to fight. I don't care, I want to live!"

How had your brother noticed that something wasn't right?

David was an athlete. He was a golfer by profession and he loved soccer. While jogging, he noticed that his right foot wasn't keeping up. He also couldn't drive the golf ball as far or walk as quickly as he could before. He became tired faster than usual when biking.

Relatives of people with a serious illness are also put under a lot of strain in a different way. And it's taken for granted that they will be there for the affected family member 100 per cent.

It was really hard. The disease progressed really quickly for David. Six months after the diagnosis he was in a wheelchair and could barely speak. I had to "translate" for him, since I understood him better than anyone else.

His illness progressed particularly quickly?

Yeah, it all happened so fast. The doctors told me the same thing.

You accompanied your brother very closely during his illness and learned to avoid looking too far ahead. In terms of your own life, do you feel like you can think about the future again?

Not yet. I can't go from 100 to zero. But I also know that I now have more time again, and I'm going to continue to take action on behalf of people with ALS and their families. In 2015, we took part in the marathon (comment: Lucerne City Marathon, Switzerland,

Team Clarke against ALS). I would love to do that again. I will always have a connection with ALS. At least I believe so.

Although your brother had a special relationship with his body as an athlete, he didn't want to believe what was happening to him?

He tried to push it aside. At the time, he called me from the hospital and said, the whole thing is probably because of stress. Maybe it's MS (comment: multiple sclerosis, an inflammatory neurological disease). On the day before his ALS diagnosis, he finally said, "It's the big one." I asked what he meant by that and he answered, "ALS." I didn't know what it was. David said I should think of the Ice Bucket Challenge. Then I knew what it was.

You knew about the Ice Bucket Challenge?

I had done it myself. And I nominated David. He



David Clarke's guitars (Courtesy: ALS Association Switzerland)

didn't respond, which was unlike him. I had no idea, did the challenge, and made a donation for MND (comment: motor neurone disease, a common term for ALS in the English-speaking

world). At the time he was already experiencing the first symptoms. That was pretty heavy.

Did you receive support after the diagnosis?

Yes. From the beginning. From Sabine Meier Ballaman¹ and Kathi Schweikert². From all sides in fact, public agencies, Pro Infirmis³. Without Pro Infirmis, none of it would have been possible. They supported me throughout all the administrative work, with forms, insurance, etc. There was always something else to deal with. Also when he finally ended up in the hospice.

You also received support in the hospice?

Absolutely. Both directly for my brother as well

Some institutions don't take in ALS patients because they're expensive and need a lot of care.

We were very welcome in our hospice. We also had a good relationship with each other, with the ALS Care Nurse and the rehab clinic. Everything always functioned as a triangle and we were in touch with each other on a daily basis.

The treatment was adjusted as the disease progressed?

Exactly. Every day there was a different situation. And you had to think, what do we do now, how can we make things better? We were constantly thinking about how it would continue.



Some of Sue Clarke's clippings and photos about her brother David (Courtesy: ALS Association Switzerland)

ALS shortens a person's life expectancy significantly. Suddenly you're facing questions about your own death. Did your brother express any wishes regarding his burial?

He said, "I want to become a tree." He wanted it to be at his golf course or in the mountains. We immediately thought of a cherry tree because of its beautiful flowers. When we put together his first living will, he wasn't having any of it. But when we were drafting the second one, I told him, I need to know what you want. Otherwise I would have been standing there empty-handed.

as for my mother, my sister and me. We all called each other by our first names and were on friendly terms. It was like a family.

Relatives of those suffering from ALS frequently remain "invisible" – those directly affected are more often the focus.

For us, it was especially difficult for family members in England. My mother wanted David to come to England, but he wanted to stay here

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³ Pro Infirmis: Center of excellence for disability awareness, based in Zurich, Switzerland

because of his kids. It was a hard situation for the whole family.

As the closest kin of someone with ALS, a lot is demanded of you. And all at once. The time for family members only comes later.

When my brother was admitted to the hospice, we knew it wouldn't go on much longer. The illness was even stronger than before. It was really painful to watch. I thought, I'll recover later.

You had a pragmatic strategy: get informed, know what's in store, and prepare yourself to anticipate whatever may come.

There were just a lot of practical questions to be answered. How long could he stay in the apartment? What happens afterwards? There was no time left to worry about myself. I would have gone crazy otherwise, if I hadn't helped out. There was nothing else I could do. It's such a big thing and it happens so fast. You know what might come and concentrate on the next steps. The next weeks. So you know how to deal with it.

You're beginning a new life chapter now – do you sometimes feel like you've had enough of ALS?

No. Right now I'm happy to have the distraction. My brother passed away on August 19. Since then I've had a lot to take care of – all the certificates, dealing with the financial stuff, organizing the funeral service, etc. At the beginning of November, the ALS Benefit Ceilidh was dedicated to my brother (comment: Scottish dance event to raise money for the ALS Association Switzerland). Of course I was there too. These sorts of events give me strength. It isn't an issue that suddenly disappears. It's a part of our family's story now.



*Sue Clarke during her speech at the ALS Benefit Ceilidh 2017
(Courtesy: Julie Collins Photography)*

ALS Association Switzerland

The ALS Association Switzerland is a patient organization for people affected by amyotrophic lateral sclerosis and their family members. The time between diagnosis and death can be one of intense emotional strain for sufferers and their loved ones. There are also a number of organizational problems to solve and legal questions that need to be answered. The ALS Association Switzerland provides support during this difficult period. It connects people impacted by ALS with each other and provides useful information about care and support, offering relief and help with related services such as disabled-accessible renovation of the home. The ALS Association Switzerland advises those affected regarding legal, regulatory and administrative concerns and supplies the latest information from the area of medicine. In doing so, it works closely together with other specialist bodies and organizations in the healthcare and social sectors.