“I think more about what I can do than my limitations”

Xavi Argemí is a young man who can’t walk or do the normal things other young people do. But he wants the world to know how happy he is. An interview published in the new online magazine "Adamah Media."

08/08/2021

Xavi Argemí is a young supernumerary member of the

Prelature who needs 24/7 attention. He can't walk or do the normal things other young people do. But he wants the world to know how happy he is. He likes to keep busy but still found time to answer our questions.

Xavi, let's begin with the basics. Where are you from and where do you live now? What did you study?

I was born in Sabadell, Spain, in 1995 and I live in Matadepera, near Barcelona. I am a recent graduate in Multimedia and I have written the book *Aprender a morir para poder vivir* in Catalan and Spanish, where I explain my life experience. The book is not yet in English but the title translated would be *Learning to die to learn how to live*.

That's a serious title! Do you expect to die young?

I am certainly aware that I will probably die sooner rather than later.

How many are you in your family and what do your parents do?

I am the youngest of nine siblings and I have a nephew and a niece.

Wow, that’s a lot!

Yes, but with all those siblings I feel a lot more supported. They love me a lot and I love them. Though we still argue sometimes!

Who takes care of you?

My mother is a nurse and is my carer. My father is a doctor and retired professor and has been looking after my medical care since I was a child.

What exactly is your condition and when did it begin to manifest itself?

When I was three years old I was diagnosed with a degenerative disease called Duschenne's Muscular Dystrophy, which causes me to lose muscle strength over time. It first manifested itself in me finding it difficult to walk or perform bodily movements in general: I fell down a lot.

What are the consequences?

Nowadays I have to be in a wheelchair and I can only move my head and hands a little, just enough to be able to use the mobile phone and the remote control to drive the wheelchair. I have to use a respirator during the night and when I have respiratory crises. I also have to feed myself through a tube in my intestine and I can only drink liquids.

How does it affect your life?

I am totally dependent on my family to do anything physical 24 hours a day.

Do you feel that you live 'less' than others, especially those of your age?

I feel that physically I do far fewer things, but I have the same worries or enthusiasms that any young person of my age might have. So, mentally I can do the same as others.

What do you miss?

Being able to walk, to do physically what a person of my age would do, such as taking part in sport or travelling.

Do you have or have you ever had a girlfriend?

I don't. In my circumstances It's just too complicated thinking about the future and what it would entail.

What kind of care do you need and receive?

In the morning, I have to be washed, dressed and lifted out of bed with a hoist into the electric wheelchair. Once this is done, my arms have to be positioned so that I can drive and use the mobile phone or the computer with a trackpad. During the day I have to change my position from time to time because of the immobility which causes muscle and bone pain. I also have to take medication for pain and to avoid respiratory complications.

Two days a week helpers come to my home to do physiotherapy to exercise my muscles and to help me avoid contractions or injuries. I need assistance to drink or go to the toilet. At night food is connected to my intestine through a tube that injects the food through a pump. It lasts until the next morning.

How do you spend your time?

I spend time reading, watching good movies or listening to music, and working on projects as a multimedia professional and on my books. I also like to be with my friends and family, generally having a good time.

How does your condition affect your outlook on life? Do you feel rebellious, bitter, desperate?

Generally speaking I accept my condition and, as I say in my book, I think more about what I can do than about my limitations. This doesn't mean that I don't have down moments and that I don't have to start every day with new courage.

Do you believe in God and does your faith affect how you cope with your condition?

I do believe in God and my faith is an important part of the meaning of my life. Christianity gives meaning to pain and hardship through the example of Christ. He understands how I feel even if I don’t know why.

What would you say to people with degenerative conditions who are demanding the right to euthanasia?

I’d ask them to think about the positive aspects of life and to think more about others than about themselves, how they can help others in difficulty. Euthanasia has a social dimension apart from the personal one. It may lead other people to do the same when in reality euthanasia does not solve anything. I think that palliative care is a much better answer to alleviate both physical and mental suffering by tackling pain and giving the necessary support to continue to enjoy life by letting it take its natural course.

Do you have a fulfilled life?

More than fulfilled, I feel happy.

How does your family help you cope with your condition?

They have always treated me as one of them, in a natural way. So I do what I can and they help me achieve what I can’t do. I share with them my sorrows, my sadness and my projects like any other member of the family. It has to be said that they also see me as a unifying bond in the family.

How do you help others and your friends with your condition?

I try to make them value the positive things in life more, so that they don’t give so much importance to the small difficulties they may have. Encouraging them, making myself available to listen to them and being able to give them some advice on how to face any moment in life. They share their projects and I share mine. They also treat me naturally.

What are your prospects? Is it possible to have hope in your condition?

I try to live in the present without thinking too much about the future, although, as I said earlier, I am aware that I will probably die sooner rather than later: in fact, there is only one certainty in this life and that is that we will all die one day, we just don’t know when or how. Death is part of life.

Do you ever get down?

I have down moments like everyone else but I get up as many times as it takes and try to cheer myself up again.

What message does your society give to people in your condition? Are you well supported by civil society?

I think that in society there are very contradictory messages. On the one hand they encourage you to overcome your contradictions and to fight to continue living and enjoying life; on the other hand, they give you a message that to live such a life, it is better not to live it as if it were a burden, that as your life is yours, you can do what you want without thinking of the consequences. So, they offer you euthanasia as a solution to your physical and mental suffering, without giving you a clear alternative that allows you to continue enjoying life with the best possible quality of life.

In this sense, they want to make you see that taking your own life in a situation of advanced or incurable illness is a good thing, which is not the case because life is totally linked to the dignity of the person. We should neither limit life nor extend it by extraordinary means; just let nature take its course.

Do you have a message for our readers?

That they should value life and try to look at the positive side of life and that they will find happiness not by thinking so much about themselves but about others. We all have our own circumstances and problems, and together we can contribute a lot to society so that it can move forward and face any challenge that may arise, such as pandemics, the fight against climate change, or research into curing or overcoming diseases.

Finally, I encourage them to read my book! In it I explain my life experience in depth. At the moment, it is only available in Spanish, although I will publish the English edition later on.

Link to original article in "Adamah"

……