



Frida



Red carpet



Coffee with friends



**Frida Gustafsson
Sweden**

My name is Frida, I am 22 years old and from the north of Sweden.

When I was one and a half years old I was diagnosed with juvenile dermatomyositis, a condition that affects all of my joints, muscles and life in general. I have been using a wheelchair since I was eight years old.

Today I am living my life to the max and I love it! I have learned how to accept, move on and make the best of my situation and take charge of my own life. I have recently started a new job where I'm even able to work full-time. I'm also active in the youth organisation for rheumatism, Unga Reumatiker; work I find very fulfilling and fun!

Many people think my life is filled with obstacles, but I disagree. I see all those things as opportunities to test my imagination, my positive spirit and as chances to have new experiences. All of the obstacles I have overcome have made me into the person I am today, and I believe I am a stronger and better person now than I would have been without my experiences.

How to overcome the challenges of living with a rheumatic disease?

Everyone has to face up to some sort of challenge every now and then – whether it's getting to school on time, changing a tyre or, as in my case and like so many others who have some kind of disability, trying to live life to the full and on the same terms as the people around you. This is the greatest challenge I have ever taken on and the main reason for all the other trials and tribulations I have faced, which have led me to where I am today.

How do you deal with a challenge like this? Live a full life where you make all your own decisions? Since I have hugely restricted and stiff joints, many of my challenges are and have

been of the physical kind: being able to go slalom skiing, compete at athletics, being able to carry my brother when he was a baby, or quite simply being able to go food shopping by myself. I have long since realised that I will always be dependent on help when it comes to certain physical tasks, and I have also accepted this fact. However, it should be up to me to decide when I want help, how I want to be helped, with what, and who I want to help me. Although many of my challenges today are of a physical nature, the psychological aspect is a large part of this. It is in my head that the journey towards independence starts. I must make the decision to work on overcoming my disabilities. I am the only one who knows what my dreams are and what I want.

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expresses it, 'You are so stubborn!'"

I'm often told that I have incredible mental strength or, as my family proudly expresses it, "You are so stubborn!". I have never been that. I have experienced many dark hours, such as when I was eight years old and went through a period in my illness when I stopped walking and had to start using my wheelchair all the time. Not forgetting the usual insecurities you experience when you're growing up, regardless of whether you have a disability or not. I got through those days, sometimes months, with the help of people around me: friends and family, who always see me as the person I am, not just a disabled person with a diagnosis.

Many people say that I am an impulsive person and I agree with them, but it's not always easy to be impulsive when you're wheelchair-bound and also suffer from rheumatism, with good and bad days. If I'm honest, there are some days when you just want to lie on the sofa and watch TV, because then you get to feel



Friends



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Riding my snowmobile



Singing

'normal', like a completely healthy person, to have an hour when you aren't thinking about an aching knee or a back that has seized up again. That is when it is good to have an outgoing personality that makes it easy to acquire friends that are just as impulsive and ingenious as you are, and to have a fantastic family that provides support and has taught you that nothing is impossible. Naturally all these people around you notice when you are having a bad day, but that is when their imagination, inventiveness and humour are most valuable. Friends who help you to forget that aching knee or rigid back just by being there and being themselves, friends that let you trail along with them on an adventure halfway across the globe, friends that lug and carry you when there are stairs in the way, the lift doesn't work or we simply want to sit in the middle of the cinema instead of where the wheelchairs go.

I am in the habit of affectionately and jokingly calling the friends that help me my slaves, because that's what they are in a way, and we say that I am the heart and they are the muscles - the evil mastermind and my sidekicks. They are not assistants, they don't get paid when they sometimes help me with my food shopping or on visits to the doctor. They do it because they are my mates and they are happy to be with me. It is largely thanks to them that this "now I intend to head off on a new adventure" flame is ignited, because I know that I can count on their encouragement and help later on to be able to fulfil

my dreams, with a large dose of humour, affection and laughter along the way.

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My family – especially my Dad – has always supported me and come up with new and sometimes slightly different solutions. Like the time when I wanted to play hockey with my younger brother and my Dad put on his skates, then mine, got hold of me under the arms, let me stand up as much as I could and then took us out onto the ice. Or the time I wanted to start slalom skiing but had stopped walking altogether and just couldn't stand up. A little while after we were at a camp where I discovered one of my great passions and a real drug for a speed addict like me, ski carting. Or when we had sports days at school and my Dad took the day off work to take me out into the woods with my assistant and friends so that I could be involved too. My family is the reason why I now have so many ideas about how to solve physical problems, so it is always possible to participate. Help is required from other people on many occasions to realise all this, but it is my responsibility to say what help I need and how I want it to happen.

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I like to say that I can achieve the same goals as my friends and do everything that they can do. I may have to achieve it by a different route, a route that might be longer and more winding and take more time than the other, but I always get to the same goals in the end.

I could write about the practicalities that help me manage my everyday life with the help of wheelchairs, 'grabbers', power wheelchairs and other inventions that provide physical assistance, but what use are all these things if I don't have the imagination and mental force to use them in new, innovative ways to improve my life? It is my imagination, my ideas and my mental strength that have driven me to break down all the 'impossible' barriers so far.

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that have driven me to break down all the 'impossible' barriers so far."

This is my story. This is me, Frida, 22 years old, with juvenile dermatomyositis and weighing 30 kilos. I live in my own apartment, I have a job, I have swum 500 metres, even though I can't float, I have played football and hockey, even though I can't walk, I have travelled to Greece by myself, I ride my own snow scooter in winter, I have competed in athletics in the Stockholm Stadium and won a gold medal, I have stood on stage as a singer, I have somersaulted in my wheelchair, I've cut wood with an axe, I've jumped on snowboard slopes in my ski cart, I fought with my brother when we were younger, I've been on TV, I did better than many of my able-bodied friends in school sports, I have bet myself that I should be able to do everything that my friends can do. I have decided to live my life to the full and I am doing it. I have never given up and never will give up, and it is with this attitude that I overcome my disabilities and challenges. I'm living my life to the full – are you?

"I'm living my life to the full – are you?"