"REGAINING YOUR INDEPENDENCE, IT'S VALUABLE"



MARIE-THÉRÉ'S STORY

This nutrition is a good thing.

From 2007 to early 2011, I was just going back and forth between the hospital and home. I was discharged without nutrition, and I was losing weight.



Reason for home artificial nutrition Enteric Myopathy

Type of therapy Parenteral nutrition



Length of time patient was not well before treatment 7-8 years

MARIE-THÉRÉ'S STORY

BRIEF STORY ABOUT EXPERIENCE ON HOME ARTIFICIAL NUTRITION

When I was hospitalised, nutrition was started intravenously as well as via a central venous line but anyway, this wasn't practical. More importantly, I had infection after infection.

Then I had an enteral trial which I did not tolerate.

The nurses advised me to request a central venous line.

It was finally in Zürich that I had a PAC (Port-a-Cath) placed in January 2011.

Having gone 7-8 years without being able to eat, this should have been placed much sooner, in order to benefit from parenteral nutrition.

It has to be done but it's a good thing; it allows me to maintain my weight and I have a better quality of life. Now I can eat a little bit. I use parenteral nutrition between 3-4 times per week.

DESCRIBE YOUR DAILY, WEEKLY ROUTINE INCLUDING HOBBIES AND ACTIVITIES:

After getting up and disconnecting, I enjoy a savoury breakfast which is my best and most important meal of the day, then I do 20 minutes of exercise.

I go out every day (weather permitting); it's a genuine need. During the nicer seasons, I go walking, Nordic walking, or use the electric bike and in winter, I walk and if the snowy conditions allow, I go snowshoeing and cross-country skiing, even if I shouldn't do too much of that (osteoporosis), otherwise I do 20 minutes on the stationary bike.

Since I have lunch late, I do not have dinner. I always go for a walk with my dog and sometimes my husband, I do some gardening, I read; social networks are also a hobby and getting together with friends for a coffee is also another small joy. I love eating and cooking but even more my grandchildren; sometimes we look after them and I couldn't go without that, it's the greatest joy for me.

I'm never bored!!



WHAT ADVICE WOULD THE PATIENT GIVE TO NEW PATIENTS?

You have to get past the fear but it's a superb aid!

You have to start with HomeCare and, with their help, learn. It's possible to do this yourself. Regaining your independence, it's valuable!

I'm asked how I can sleep at night... I sometimes forget that I am not connected some nights and to look for my pouch when I get up. But it's a part of us after X years.

FEEDBACK

The online shop is great; I'm independent.

I rarely have any concerns. An order is placed, is delivered, and if there's a problem, they call me.

If I have any questions, I get in touch with my contact person and I get an answer quickly.





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