

From the diary of Stief Dirckx

“My new dentures allow me to enjoy my food again”

Because of their limited mouth opening and the increased risk of sustaining minor wounds, eating is often a very painful experience for people with epidermolysis bullosa (EB). Their teeth are damaged and sometimes wear away completely. Do implants provide a solution? Let's read the response in the diary Stief Dirckx kept when he received new dentures.

September 2008

As I only have a few lower teeth left, biting and chewing is becoming increasingly difficult. My tongue and gums are becoming increasingly painful when I eat. This cannot go on. I can only eat porridge and mashed potatoes and I haven't enjoyed a meal for as long as I can remember.

My regular dentist, who specialises in prostheses, and an oral and maxillofacial surgeon look for a solution together. Regular dentures immediately fall out; my mouth won't be able to stand them. Putting in individual pivot teeth is not an option either, as too many teeth would then have to be implanted. Using implants, with prosthetic teeth the size of a full denture on top seems to be the only remaining solution.

There are two possible obstacles: will the bone in my lower jaw be thick and strong enough and will my mouth opening be big enough to allow for such a procedure? A scan reveals that the lower jaw bone is good, so I'm glad this problem is quickly resolved. My mouth opening is a bigger problem. As there are lesions at the corners of my mouth and there is scar tissue on the inside of my cheeks, I have a very small mouth opening. The consultants therefore need to look for the smallest possible instruments and prosthetics to ensure everything fits into my mouth.

February 2009

As a full-sized prosthesis will be placed on top of the implants, first all remaining teeth need to be extracted. Two same day surgeries are scheduled to do this: one procedure to remove the lower left teeth and another to remove the lower right teeth. This way, the narcotics are limited and my mouth is given enough time to heal. Shortly after the first procedure on 13 February, it becomes clear to me that I will be forced to eat a lot of mashed potatoes and pasta for quite some time still, instead of my favourite fries ...

March 2009

Shortly after the second procedure on 6 March, an unexpected problem occurs: after the final teeth were extracted, my gums become inflamed. I will have to take antibiotics for a while. The next step is postponed as it is too dangerous to proceed now. I will need to learn to be patient.



source: www.onlinelibrary.wiley.com



June 2009

Another scan is performed to check the strength of the bone. Fortunately, the inflammation has gone completely. I then get a consult to discuss the location of the implants. I decide to first go on holiday in July. The doctors cannot schedule the procedure in August; they're entitled to their holidays too. September it is. I had hoped to get all of this misery behind of me in six months' time, but that won't be the case, it seems. Disappointed, but hopeful, I count down the days.

September 2009

Placing the implants will be the most difficult step. They will need to drill into the jawbone. This is where the implants will be placed. It is important to space the implants at regular intervals in order to secure the denture and prevent it from moving around.

It is 4 September and the big day has arrived. This surgery requires heavier sedation with intubation, but it can be performed during a day admission. When I wake up, my mouth hurts more than after the previous surgeries. It apparently took quite a bit more effort to place one of the implants as far back as possible. The other three implants are in a row in the front. My mouth has more sores and blisters than usual, but I have forgotten all that in the space of a couple of days.

A week later, I have to go in for a check-up to make sure that everything is still in the right place. Looking in the mirror, I see three silver heads sticking out from my gums, and I can hardly see the fourth head. Over time, the swelling in my mouth should subside and the gums should repair themselves neatly around the implants.

A few days later, I panic. While at work, I suddenly feel one of the heads come loose. At first, I think that I'm imagining it, but it falls out completely about an hour later. Oh dear, that can't be a good sign. Has all this been for nothing? I immediately call the hospital and get an appointment for two days later. The specialist immediately sets my mind at ease: the implant itself did not fall out, it was just a screw that was used to close up the implant. Phew! You have to imagine an implant as a sort of plug into which the denture can be fixed later on. The screw is just a temporary protection.

Because the screw was out for two days, the gums have already grown over the implant. They have to be opened up once again in order to screw it back in. A little painful, but I'm glad that it's nothing worse.

October-November 2009

Now everything needs time to heal, and the implants must be given time to grow firmly into the jawbone. I only have to make sure to not put too much pressure on the implants while eating during the initial period. Several screws come loose during that period, but I immediately know that it is nothing serious. I just have to travel back and forth to Leuven to have them screwed back in and I can move on.



source: UZ Leuven



living with EB

December 2009

Now that the implants have had sufficient time to grow into the bone, the specialists examine how best they can fit a denture. Easier said than done. There is not enough room around the gums to guarantee sufficient stability for the denture. So the oral and maxillofacial surgeon is called on. He is tasked with creating a better base for the denture. On 15 December, I am once again lying on the operating table. Because of the lesions, my bottom lip has almost attached itself to my gums. The surgeon makes an incision and places a piece of donor skin between them so that my bottom lip cannot attach itself to the gums and the space can remain open.

In order to shield the wound and enable it to heal, and in order to maintain the newly created space, the surgeon applies a liquid resin in the space between the bottom lip and the gums. The resin has to stay in place for at least two to three weeks in order to allow the wound to heal.

This period was the toughest of the whole process for me. I have the feeling that I'm walking around with an oversized mouthpiece (the kind boxers use). I find it difficult to speak, and eating is even more difficult than before. And all of this is happening during the Christmas period, when everything is geared towards partying, eating and drinking. Enjoying all of that will not be on the menu this year.

January 2010

The resin can come out in early January. My mouth finally feels normal again. The specialist can now start on the denture, which I hope will be the last phase. I will need to come in for a consult seven times in total for the denture.

First, the specialist uses a sort of paste to make an imprint of the mouth and the gums on which the denture will rest. It soon becomes apparent that existing methods for creating an imprint cannot be used, because my mouth is smaller than the smallest available mold. The specialist therefore has to manually create an imprint, and it's painstaking work.

In this phase, it also becomes clear that I will need a denture that is permanently screwed in rather than a denture with magnets that can be taken out when necessary. This allows for a smaller denture to be installed.

February 2010

After a few weeks, a first rough version of the denture is ready. Grrr, this is where problem number two comes to light. The denture has to be screwed onto the implants, but none of the wrenches for doing this will fit in my mouth. A miniature wrench has to be specially ordered. This leads to more delays, sigh.

April 2010

We finally did it, everything went well. During the final consultation, the specialist checks whether the denture remains firmly in place and does not cause any discomfort. I find the end result fantastic. It far exceeds my expectations. I often cursed the many practical problems out loud or silently, it seemed to last forever. But I will soon forget all of that. My eating habits have changed significantly since getting the denture. First of all, I can once again enjoy what I have had to avoid for over a year: fries! Mmm...



source: www.bicon.com



source: [UZ Leuven](http://UZLeuven)



But there are other benefits too. Since then, I have had fewer problems with blisters and sores in my mouth, and I also feel like I have fewer problems with the oesophagus because I can chew up everything better. I now feel a lot more confident when I have to eat something. I now regularly try out new foods, which I used to avoid because they were difficult to chew or because I was afraid of choking. I can also eat more food without having to mix or crush it: it tastes better and my dad has less work in the kitchen.

The financial implications are less positive: dental implants are not reimbursed by the ordinary health insurance in Belgium. Fortunately, my health fund and hospital insurance covered some of the outpatient and day clinic costs, but I was - still - left with a large sum that I had to pay myself.

I would like to use this opportunity to once again thank all the doctors of the UZ Leuven who helped me throughout this period of around sixteen months: Prof. Vinckier and Dr. Verhaeghe, Dr. Coelst, Prof. Schoenaers and Prof. Naert. Although I may have been somewhat of a guinea pig, they accomplished their extremely difficult task to perfection!

Stief Dirckx

Stief Dirckx is 37 years old, lives in Hamont-Achel (Belgium), and works as a software developer. He has dystrophic EB. He became the chairman of Debra Belgium in 2003.



source: Stief Dirckx

The above diary fragments are about his lower denture. After getting the dental implants on his lower jaw, Stief started using his teeth more and started biting and chewing harder. This caused his upper teeth to wear down and break quicker. In 2013, Stief decided to have his upper teeth replaced by implants as well. This was a very difficult procedure, as the bone in his upper jaw bone was not strong enough, and his implants let go. After consulting physicians abroad, a solution did present itself. A professor from Austria put in a new type of implants, which did stay in. On top of the implants, dentures were placed, which were made in the US.

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Contact



Debra Belgium vzw
Vereniging voor Epidermolysis Bullosapatiënten

Rue Piralewe 1 | 4600 Lanaye (Visé) | T 04 267 54 86
info@debra-belgium.org | www.debra-belgium.org

