Podcast III: Aphasia from the perspective of patients and their families

"Understanding aphasia" from different perspectives. In our podcast series, we provide insight, clarify and create understanding for a disease that changes language and life. My name is Ines Conzett, I am a speech therapist and I am delighted to be able to shed light on the topic of "Aphasia and interprofessionalism" in this podcast series. I am extremely pleased because these are precisely the two topics that are of interest to me in my everyday professional life.

Presentation

Ines Conzett (I): I am joined today by Urs-Peter Michel and his wife Verena. I am very pleased to be talking to you about aphasia and interprofessionalism. It is important for our listeners to know who we have here. I'm going to start with the women. Verena, would you like to introduce yourself very briefly?

Verena (V): I'm Verena, Urs-Peter's wife. I've lived in Basel for many years, but I originally come from Zurich, where I grew up. After training as a music dealer, I helped out at Musik Hug in Basel, where I stayed. I later moved to Theater Basel, where I worked at the box office for 35 years, most recently as deputy manager. Theater has always been a great passion of mine.

I: And that's where you met Urs-Peter?

V: No, that was later - with the tango. I had wanted to learn Argentine tango for a long time. When I didn't have a partner who would do it with me, I just started. And then I got to know Urs-Peter.

I: How many years have you been together now?

V: In about a week it will be 20 years.

I: Very nice. And you, Urs-Peter, you're a Basel native in that case. You were born here.

Urs-Peter (U): Right, yes, yes. I'm a typical Basler.

I: And what did you do for a living?

U: I first worked at a bank, where I was involved in organizational matters. After that, I started helping older people and supporting them in their everyday lives. And then I realized that I wanted to work less. At the bank, however, they said no, I couldn't do that.

I: At the bank where you worked? So a reduction was not possible.

U: Exactly. And then I decided to stop working on the bench and asked myself the question: "What can I do? Where am I good at?" I realized that I like supporting people - whether older or younger, who don't know how to do certain things. So I started doing just that: Helping with financial issues, organizing meals or providing support in everyday life. I realized that this work suited me - and made it my profession.

I: In other words, you made the switch from banking to social work, inspired by your experiences?

U: Yes, exactly.

Review: The stroke

I: Something happened in March 2019 that you will probably never forget. Can you tell us about it?

U: Yes. I was at the bank and had been feeling unwell since the morning. The right side of my body wasn't working properly and I knew something was wrong. I felt very unwell. So I went home and from there I took the streetcar to the hospital on my own. The shocking thing is that you can feel that something is wrong but you can't do anything. You can't call anyone and ask for help. It's amazing that it still worked. In hospital, it quickly became clear that I'd had a stroke.

I: So you went to the hospital on your own despite your symptoms?

U: Exactly. I pocketed some more money and set off. At the hospital, they immediately realized that something was seriously wrong. The doctors examined me and took the next steps.

I: Were you still able to speak at that time?

U: No, not really. Not a single word came out. My right side got a little better for a short time, but apart from that nothing worked.

I: In other words, from one moment to the next you were confronted with a stroke and aphasia. Did you know what aphasia was beforehand?

U: I wasn't familiar with the term, but I knew that there are people who suddenly can no longer speak or can only speak to a very limited extent. I was already aware of that. But the shocking thing is that you can sense that something is wrong, but you can't do anything. You can't call anyone and ask for help. I couldn't even let Verena know that I wasn't feeling well. That was a terrifying experience.

I: It's extremely important to act quickly, and you managed to do that. Verena, how did you experience this day?

V: I was at work and had sent him a text message to ask him something. I was surprised that he didn't reply because we normally had regular contact - there was always a "Where are you?" or a "How are you?". That morning he had told me that he wasn't feeling well, but I thought it was a headache or migraine, nothing serious.

When I got home and he still wasn't answering the phone, I got restless. We weren't living together at the time, but I had a key to his apartment. I packed my things and drove to his place. There I met his neighbor, who asked me how he was. I had to tell her that I hadn't heard from him all day. She then told me that she had seen him at lunchtime and immediately realized that something was wrong. She called an ambulance but told him she was calling a cab so as not to worry him. She has two doctors as sons and knew immediately that it was serious. She got him a chair, but in the meantime he had already taken the streetcar to the hospital. The ambulance arrived five minutes later. I only found out about it later. When I heard about it, I went to the hospital straight away. I have a good friend who works there. I called her and asked where I could find Urs-Peter, because I had no idea where he was. She was surprised that no one had informed me yet, but luckily she was able to tell me where he was.

I: It's impressive how you both handled this situation. Many people in a similar situation have the same problem: they want to inform their partners or family members but are unable to do so. It is often difficult for medical staff to find out exactly what has happened, but despite your aphasia, you managed to get to hospital. This shows that you were fully conscious and oriented.

U: Exactly.

I: That's an important point: people with aphasia can think clearly and are oriented - it's the language that doesn't work. Verena, how did you experience the contact with the doctors? Interprofessional collaboration plays a major role.

V: I found it very positive that I was immediately accepted as a partner, even though we weren't married at the time and weren't living together yet. I was his only caregiver, as he had no siblings and his parents were already deceased. I was involved in all decisions.

We had no idea what effects the stroke would have. A doctor told us that the speech center in the brain was affected, but I could hardly imagine that.

One particularly difficult moment was when a doctor filled out a form and asked Urs-Peter to decide whether he wanted to be kept alive in the event of another stroke. He couldn't grasp this at all and only answered "Yes". The doctor asked: "If you have another stroke, should we let you die?" And he said "Yes" again.

I was shocked and immediately said: "No, certainly not!" Today we can laugh about it, but back then it was serious. If I hadn't been there, they might really have let him die.

I: Communication is essential in situations like this. You were lucky that you, Verena, were there for Urs-Peter. But there are many patients who don't have this support. Thank you for sharing this impressive story with us. It shows how important quick action, medical care and support for relatives are.

Life and relationships after a stroke

I: Urs-Peter, you went into rehabilitation after university hospital. Do you remember? Have you made any progress? What was it like for you? What do you remember about rehabilitation? What therapies did you have there?

U: Oh dear, so many. I had lots of different therapies every day, I can't even list them all. It was insanely special. And the food - watch out! - the food was far too good. I ate too much at first and then said that I only wanted half a portion.

V: No, you didn't say anything.

U: That's right, I haven't spoken much yet.

V: I took over for him and said: "He only gets half a portion."

I: How did you perceive communication at the beginning? Were there any strategies for communicating with each other?

V: Somehow he was able to make himself understood when it came to important things. I had the feeling that he knew maybe ten words. After a week or two, it was maybe 50 words. It went really slowly. But because I know him very well, I often sensed what he meant.

I: Urs-Peter, we met two years ago. Today I see you again and I have the impression that your language has improved. How do you see that?

U: Yes, it has improved, but I still find it difficult to speak sometimes. Sometimes people don't even notice that I have difficulties. At other times you notice it clearly. It's a bit more difficult now when I'm talking.

I: Can you describe when it is easy for you to speak and when it is difficult?

U: I can't say for sure. Sometimes it just goes like this - blub, blub - it works. But when I want to say something specific, it doesn't work.

I: Does that also have to do with the person you are talking to? Is it easier when someone speaks slowly and takes their time?

U: No, not necessarily. Sometimes it works, sometimes it doesn't - quite simply.

V: I have the impression that stress plays a role. When he's under pressure, even words that he usually knows disappear.

U: Yes, when I realize that someone doesn't understand me, I try to make gestures or show them with my hands.

I: Are there any strategies that help you when you can't find a word? Do you use a computer, tablet, books or drawings?

U: Yes, when I realize that someone doesn't understand me, I try to gesture or show it with my hands. Or if I want to tell someone that I've put a letter in the letterbox, for example, I can't write it. So I just take a photo and send it.

V: At first, people didn't understand and asked: "Why are you sending me a photo?" But now they know that this is his way of communicating.

U: Exactly! Or if I want to tell someone that I'll be late, I take a photo of the streetcar station or of lots of people to show that I have to wait.

I: You used to sing in the church choir and now you sing in the aphasia choir. What is that like for you?

U: I can't really sing - not the lyrics. But I can sing the melody.

I: That surprises me! You can speak so well, surely you can sing too?

U: No, the lyrics don't work. I can hear the melody and imitate it, but I can't say the words. Others in the choir can speak but can hardly walk. Everyone has their own difficulties.

I: This shows that people with aphasia can also take part in singing, even if it is linguistically difficult.

U: Yes, that's important to me. I used to be in the church choir, and it sometimes pains me that it's not like it used to be. But I still come every time because I enjoy it.

I: You weren't married yet when Urs-Peter had the stroke. What was that time like for you, Verena?

V: It was a big shock. I imagined growing old with him - and suddenly he could have died. I asked myself: if he was no longer there, what would still make sense for me?

I: That sounds like a very difficult time.

V: Yes, but it also gave us strength. I asked him: "Do you still want to be with me? Should we move in together?" It would be easier that way than constantly commuting between two apartments. After six months, we said: "Why don't we get married?"

I: And you're even dancing the tango together again!

V: Yes! Although it was difficult after the stroke, especially for him as a man - he has to lead in dance. But a lot of things came back over time and now we're dancing again.

Wishes for people with aphasia

I: Urs-Peter, when you think about other people with aphasia - what would you wish for from society?

U: Oh, that's difficult. Everyone is affected differently. But I think the most important thing is Don't give up! It takes time. Just keep going.

I: And you Verena, what would you wish for from society and the healthcare system?

V: Our situation is special - I am retired and can therefore take intensive care of Urs-Peter. But many of those affected have no one to support them. They absolutely need help, because there are many things they can't cope with on their own. Just a few hours of support a week would be a great relief - whether it's for administrative tasks or to do something together, go to the theater or out to eat. It is important that people with aphasia can participate in life.

U: It takes time! Patience and support are essential.

V: It is particularly difficult when you can no longer do basic things yourself, such as making phone calls or arranging appointments. This is where you need people to help and support you.

I: Thank you very much, Urs-Peter and Verena, for your openness and this valuable insight! I would also like to encourage our listeners to listen not only to the perspectives of those affected, but also to our other podcast episodes. In the episode with Prof. Dr. Susanne Wegener, the topic of stroke is examined from a medical perspective. We also talk to nursing staff and speech therapists about everyday clinical practice and the challenges of therapy.

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