

Podcast I: Aphasia from a scientific perspective with Prof. Dr. med. Susanne Wegener

"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.

I: With me today is Susanne Wegener. You are welcome to tell us how we know each other and introduce yourself.

S: With pleasure, thank you Ines. So my name is Susanne Wegener, I also work interprofessionally, every day actually. And we know each other from the SNS Commission Team Interprofessional Neurology. I'm a doctor, a neurologist at Zurich University Hospital and a professor at the University of Zurich, and my specialties are actually strokes and headaches. But I deal with aphasia very frequently every day. I'm really looking forward to talking to you.

I: Very nice. Aphasia. What does aphasia mean? Can you explain it to us, in simple terms that everyone can understand, aphasia?

S: Yes, aphasia is first and foremost a speech communication disorder and this must be differentiated from dysatria. That's always the first thing you learn in medical school. In the case of dysatria, the speech implements do not work, so to speak. So you speak indistinctly or slurred or strangely, but you understand the language or you understand what it's about. And with aphasia, there is the problem that the language may not be understood correctly in terms of content, or that what you understand and want to say does not come out correctly. In other words, the language you produce is not correct. We differentiate between fluent and non-fluent aphasia. With non-fluent aphasia, you simply can't produce speech fluently, but you may be able to understand quite well what others want you to say. And in the case of fluent aphasia, you may produce a lot of speech, but it may not be correct and you may not understand what others want from you at all.

I: So you're a neurologist and that has to do with language, you tell us. And how should we imagine that? What happens to these people? So what could be the causes? When do we talk about aphasia? What could be the cause?

S: So aphasia has its basis in the brain, a disturbance in the function of the brain. And we often see this very acutely, i.e. very suddenly. And in my specialty of stroke, it's a very common symptom, meaning that speech suddenly stops functioning. And examples of this can be that those affected simply can no longer speak, not at all, or that they can only say yes, yes, yes. Or that they simply don't understand what is happening at all. And that when you ask them to do something or talk to them, they don't react in the way you're used to. And the causes can be a



stroke, for example, but also other illnesses. It usually affects the left side of the brain, the left hemisphere, we say. And because the left side of the brain also controls the right side of the body, i.e. motor function and sensation, this aphasia is often accompanied by right-sided paralysis or impaired sensation. But it doesn't have to. These are the acute disorders. Aphasia can also occur after an epileptic seizure, for example, or if you have injured yourself, if you have injured your brain, for example in an accident. However, it is also possible that aphasia is part of a chronic neurological disorder that develops over a longer period of time and that the symptoms develop gradually. I'm thinking of this, for example. This can also go hand in hand with aphasia.

I: You know that you have to react very quickly in the event of a stroke. Why is that the case? Well, sometimes, as I'm also a clinician, you hear, "Then suddenly I couldn't talk any more. Then I went to bed and thought it would be better tomorrow". Then you simply reacted far too late. Why is it important to react so early? When you realize I can't talk anymore, I have a sensory disturbance or my arm is limp.

S: If the cause is a stroke, for example, then you can save a lot if you treat it early. For example, if a blood vessel that supplies the left side of the brain is blocked, and this is the cause of the speech disorder, of the aphasia, then you simply have to go to the hospital immediately with the ambulance so that, for example, a so-called lysis therapy can be carried out to dissolve the blood clot. And then it may well be that the aphasia disappears or improves significantly. And if you wait too long, then that part of the brain will go under. And then you no longer have such a good chance of it recovering well. And, of course, aphasia is always a sign that something is wrong, something serious. Unlike a cold, neurological diseases are often very serious. And there could be even more symptoms. In other words, it's certainly not a good idea to lie in bed with aphasia and say it will be better tomorrow, but it's something you should seek help for immediately.

I: You mentioned lysis therapy. How would you describe this? The patient comes by ambulance or directly to the hospital. What exactly happens there?

S: Well, it's very stressful. It's all very orderly, but very fast. You are admitted to a stroke unit or a stroke center. There is an interprofessional team of nurses and doctors from different disciplines. Radiology, that's where the images of the brain are taken and assessed. Or who may be able to remove the clot mechanically using a catheter. The neurologists, who briefly ask what has happened and carry out a short examination. At the same time, blood is taken and an ECG is written. And then you get a CT or MRI scan as quickly as possible. This is a neuroradiological method to take a picture of the brain so that you really know what's going on and how best to treat it. And the treatment must then be given as quickly as possible. So it's often a very stressful and fast procedure. And it's always very important for the whole team to get all the information very quickly. You also have to communicate and talk to each other a lot so that things go as quickly as possible for the patients.

I: And if we now assume that it was possible to react quickly. How is it going for someone? What happens next? You were able to do all the tests, you were able to do the lysis successfully. What can the patient expect in the coming weeks or even months?



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S: It's very, very different and depends very much on what the problem is and how well the therapy responds. Most people are first admitted to a monitoring ward, which is often a stroke unit, and are really continuously monitored and asked again and again how they are doing, examined again and again. If you have aphasia, you are also repeatedly monitored to see whether your speech has improved or your speech comprehension has changed. Because in the first 24 hours it can move in all directions. It can recover incredibly well. So it may be that a severe speech disorder and paralysis really does recover completely. But it can also be that there is another stroke or that the situation worsens. So it's a very vulnerable phase, the first one or two days. And it's important that you know that you're still there, but then, fortunately, we have a healthcare system where we have really trained staff, a great team that knows its stuff. And the treatment, regardless of the clot, starts in the stroke unit with therapists, speech therapists, speech therapists who know about aphasia, who assess it correctly and try to provide support right from the start.

I: I think another important point is what happens to the relatives. I always imagine that you are so affected, you can't communicate, you come to a hospital and the team is very professional and so on. You're used to it, but for the person affected it's usually the first time they've experienced it. How do you deal with relatives in these situations? Are they also looked after? What happens in the stroke unit?

S: Yes, that is very, very important. Yes, they are also looked after. They are also very important because we often need information very urgently and those affected are sometimes unable to communicate it, especially in the case of aphasia. When patients have aphasia, they can't tell me that something was wrong the day before yesterday. And that can be decisive in how we choose the therapy. Or they may not be able to tell me that they are still taking blood thinners. That can be very, very important. So we always contact the relatives and always try to have them with us at the beginning. At least for a brief conversation. In all the hustle and bustle, there is always someone from the team, often from nursing, but also someone from us doctors, who briefly explains what is happening now, that it all has to happen very quickly, that unfortunately we don't have that much time to talk any longer; they get the information they need; they explain, we take a picture, we start the therapy and then we come back in peace. Then, of course, they can see their relatives. Of course, it's also incredibly important for the patients that someone from their family is there.

I: You mentioned that interprofessional collaboration is very, very important. And you also work at the . Why is interprofessionalism so important to you?

S: Because we simply bring in different expertise, different training that is complementary. And each alone is not enough. And we will certainly also talk about aphasia, which I think is a classic example, where we on the medical side already recognize it and also understand a little bit what could have happened there and that is important for us for the diagnosis, but therapeutically we are very close and without experts we would not be able to help at all. And in the case of aphasia in particular, we need a lot of guidance and support from the medical side as to how we can actually deal with those affected correctly and how we can provide them with the best possible support.



I: Aphasie-Suisse also has very clear rules or tips on how to deal with aphasic people. You described quite well at the beginning that the whole speech system is affected, in contrast to dysarthria, where it is purely a motor problem. In other words, you could assume that the patient can't read, can no longer recognize letters, can no longer write their name with aphasia. The rules that aphasia dictates in Suisse are really eye contact, the inclusion of non-verbal communication, images, the inclusion of everything. And time is a very important factor. Do you have time at a clinical age?

S: No. No, we don't have that. Especially in such an acute phase, we don't have that. And unfortunately, when someone comes in with an acute stroke, for example, we often don't have the speech therapist with us. This means that we can only try to help those affected with our meagre resources. But what is important, and I always try to do this, is to approach anyone who you know needs help, to show that you understand them. For example, if you realize, aha, the person has aphasia and is now unable to produce speech, that you make it clear that you say, ah, that doesn't work with speech. I understand that, it's because of the stroke, isn't it? We'll look into that, we hope it will get better. That you don't give those affected the feeling that you just accept it, but that vou understand it. And that you also try to see if they understand you, even if they can't produce speech, of course. That is very, very important. Sometimes you have to use simple means, so you can close your eyes, you can open your eyes. And it's essential that you make an effort, at least for a short time, to find out whether the person, even if they can't speak, is able to roughly understand what's going on. But also with the understanding that this is an exceptional situation. which is probably incredibly stressful. You can't come up with complex content. This is also very, very important, for example, for studies or for consent, for any kind of intervention. You can't assume that people without aphasia are even capable of reading and signing a very complicated consent form. Of course, this is even more the case with aphasia. In other words, you have to be aware at the moment that you have to make a decision for this person to the best of your knowledge and belief. Including the relatives, of course, if they are there.

I: A very difficult task for patients with speech disorders. I think that's always a real challenge. The human touch, which you described so beautifully, is the be-all and end-all. Putting yourself in the person's shoes, verbalizing what you see. It's difficult for them at the moment to talk and deal with this problem. But none of us can do magic. The problems of not being able to communicate are massive. And that sometimes requires everyone at the bedside. And after you've been to the stroke unit, if it's a severe stroke, where do the patients go? What happens during the course?

S: This is often followed by rehabilitation in a rehabilitation clinic, which can last for weeks, because you can still make so much progress in this initial phase, both in terms of motor skills and speech and many other limitations that can result from a stroke and that are often undetected in this acute phase. For example, things like dealing with numbers or reading. We completely ignore this in the first day or two and we don't have time to look at it properly. And then, when the patients are feeling better, they suddenly realize that they can't do the things they were able to do before. That could be reading or watching TV, movies or something like that, but it could also be that they can't use their cell phones properly. The apps they normally use to get through life and manage



their account suddenly no longer work. That's extremely important. And that takes a lot of time and therapy and support. And it also requires interprofessional work.

I: It used to be assumed that there are certain windows when rehabilitation makes sense. Can you say something about the plasticity of the brain? Or can the brain learn indefinitely? Or is there really a phase where you can say, yes, until then, or something. Can this be determined in terms of duration?

S: I would try not to do that. You always know that the acute phase is when things change the most. That's when there's the most opportunity to improve things. That's why we always encourage those affected to go to rehab. After all, it's not the best thing for everyone not to go home straight after hospital, but to go to rehab instead. You might even be able to walk quite well, but you have aphasia. And then to explain to those affected, do it now, because your brain is still in the best position to adapt quickly and learn it again quickly. And yet you always learn, you learn all your life anyway and it is also quite possible to change something again in a chronic phase with good therapy or perhaps with new therapy or new motivation.

I: Well, it's never too late. It always makes sense to continue investing with motivation or a specific goal after a period of illness.

S: Absolutely, yes.

I: Many patients are probably also afraid that this could happen to them again. Are there any figures or important things that you can say can be done to prevent this from happening?

S: Yes, especially when it comes to strokes, that can always happen. The risk is also greatest in the first year. But strokes are so common that we are all at risk of one at some point as we get older. And the best thing you can do is to pay attention to the so-called risk factors or control them as much as possible. Again, that's high blood pressure, smoking, sugar, getting more exercise, being active. These are the things you can do. And that is of course also an important part of treatment and rehabilitation. And it's also super interprofessional, so that you're not always just told what to do, but that you also learn a bit about how to actually do it. How do I integrate sport into my life now? How do I stop smoking, for example? This is also very interprofessional. That's very important. And in the end, you just have to be lucky that it never happens again. And fortunately, that's the case for many people.

I: Interprofessionalism is a topic that has probably become much more important in recent times. Medicine has become more complex. Yes, there are many specialties. The FOPH has also carried out a study on this. At the SNS, you are concerned with interprofessionalism. What are the things that make this successful? Factors that make interprofessionalism successful?

S: Well, for one thing, it's a good team atmosphere, not a hierarchical system, but it's very important that everyone appreciates each other, appreciates each other equally. And I think that's very often the case in our commission anyway, because we all bring different expertise to the table. Perhaps 50 years ago, working together was different. And today, therapies, therapists and nursing staff are so well trained that it's absolutely clear that we simply don't have that much knowledge and expertise on the medical side. And everyone has to focus a little on their own



specialty. And that's why the main requirement is to treat the different professions with respect and to take an interest in what the others actually do, how they actually do it. That's sometimes difficult because of the little time we often have to get a taste of it. I often think I should go back to speech therapy and see how it actually works, don't you? That would certainly help me a lot. Sometimes you just don't have the time. But you gain great insights through commission work like this, and through projects like this in general, and they are very enriching. So interest, curiosity, appreciation. And there is simply a great interest in interprofessional collaboration overall, because you are more productive, it's better for the patients. And there are also many new job profiles that are emerging, such as Advanced Practice Nurses APN or Physician Assistants, i.e. different job profiles that stand between the therapeutic professions and the medical professions, which can do completely new things and thus take on other work and also bring new expertise. So there's a lot happening right now.

I: The SAMS has also published a charter on interprofessional collaboration. I think it would be valuable for all people who work in the healthcare sector to take a look at it. In addition to the things that you have now said are very important, such as communication at eye level, appreciation, curiosity, it also describes that it must take place on the executive floor. So not just nursing and therapists at the bedside, but that it also has to be an attitude on the part of the institution and even the funding bodies. What can you say about this? Are there differences between the inpatient and outpatient sectors?

S: Yes, there are definitely different challenges, because it's often also about the financial aspects. So even if the appreciation is there, work can only be successful if it is somehow remunerated, otherwise it doesn't work. And it's perhaps a little easier in the inpatient sector because the roles are clearly defined. Or in these new job profiles, work can also be delegated to doctors. And in the outpatient sector, it is perhaps sometimes a little more difficult because, as I understand it, there is a huge shortage of therapists in various specialties. As far as I know, speech therapists are a very sought-after profession. And we notice that too. Our patients can't find appointments. That's really very frustrating and a shame, isn't it? And I also hear again and again that the service is often not properly compensated. And especially the consultation, which is also very important, probably in your work, that it can't be billed properly. Of course, that's a shame if you only have a very short time to do your therapy and would actually like to do a lot more. But this is no longer compensated. I don't know if that has answered the question correctly. But yes, I think the challenges are different for outpatients and inpatients. I think rehab is a great situation. Because the therapeutic aspect is very much in the foreground and the medical aspect is perhaps a bit in the background.

I: And also consistency. As you described so well, the acute sector is hectic. It's about life and survival. And in rehabilitation, you have patients for longer. You can define goals. Everyone can contribute to the goals. And in outpatient care, it's spread out again because the distances are simply longer. You're no longer simply next door to each other. And that's why interprofessionalism probably has its challenges at every stage. And we probably agree that interprofessional collaboration can actually produce the best results. And it is also described in the charter that it is also very important to involve the patient. We have our studies and our guidelines, we have our



ideas on how to provide the patient with the best possible care. But it is very important that we also decide together with the patient what is important and what is not right for them. And especially with people with aphasia, as you have described, this is even more challenging.

You are also active in research, not so much in the aphasia field, but what else would you like to work on when you are not on the Stroke?

S: So with research into stroke, how we can make the therapies work better, how we can tailor the therapies to the individual, so that we can better understand which therapy is best for whom and what the prognosis is for the individual affected, based on the patient characteristics, but also on the imaging. That is one thing. But we also do a lot of research into headaches. That's another of my hobbies, where we also work together with linguists. These are linguists or language experts. But it's less about aphasia and more about the conversations we have about headaches and analyzing and understanding what we're actually talking about. How are headaches actually described? Because you can't see pain, you have to communicate it. And also, how do the conversations go, how satisfied are the patients with the conversations and what is really important to them. And we doctors in particular, again we don't have much time, the report has to be typed up, maybe people are writing on the computer during the consultation or we don't always offer the ideal consultation situation. And that's the case with headache patients. And now you have to imagine someone with aphasia sitting there. Their needs are completely different. It takes even more time and we reach our limits very quickly. And improving that is one thing, and I know that a lot of research is also being done here, not by me, but by colleagues of mine, who also want to develop support tools for people with aphasia, which might help to make language more understandable or make what is available in language easier for others to communicate with. But I know that we are still at the very beginning.

I: Wow, we're excited to see what else can and will await us. And as you described so well, communication is incredibly important in all areas of medicine. Especially in aphasia, because one person is affected and has limited communication skills, but I think communication is immensely important everywhere in the healthcare system.

Finally, if you could make a wish for people with aphasia, what would you hope or what would you wish for the healthcare system that it could somehow be a little better or different? What do you think is really important?

S: Well, I just think there are more opportunities for therapy and also a slightly better understanding of aphasia and what you can expect and what support options are available. So it's not such huge things that I would dream of, but I think there is a lot that can be achieved in the areas of knowledge transfer and therapy transfer. I don't think there is a magic bullet. There is also no pill for aphasia, you simply have to approach it individually and therapeutically. And I can imagine that aids, well, I could imagine if I were a sufferer or a relative, if I had something like this in my hand that gave me a few tips on how to deal with a situation where my husband, for example, simply doesn't understand me. And in this situation, what can I do specifically? Is there a picture book or a card or an app that I can use? Or is that perhaps counterproductive because I don't need to use so



many electronic aids? I think aids for relatives would be very important. And also for the medical profession, right? How do I actually do this properly? I don't think we invest enough time in this.

I: Thank you very much for the very impressive descriptions. I think we all know a bit more now about aphasia, the acute sector, rehabilitation, the outpatient clinic, interprofessionalism, which is very, very important, the time we have or don't have.

Yes, I think we've seen a lot and I'm looking forward to talking to a speech therapist and a nurse in the next podcast series that we have, who might be able to give us some more tips. And also with a sufferer and his wife, who can tell us exactly from his perspective how they experienced it. The lice, whether that was possible and the conversations and not being able to communicate. I'm looking forward to the next series and thank you so much, Susanne, for allowing us to talk to each other like this. Thank you.

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