

# DO YOU REMEMBER?

## NO, I DON'T

September 21st is World Alzheimer's Day. A new case of this disease is diagnosed somewhere in the world every 4 seconds. It is forecasted that in 2050, more than one million Poles will suffer from Alzheimer's, three times more than today. Dr. Justyna Hryniewicz from Dr. Hanka Hertmanowska Memorial Neurological Non-Public Health Care Center and MS Treatment Institution advises how to work with patients and how to help them.

*Translated from: „Sukces po poznańsku”, September 2018*

### **Where does this disease come from?**

Justyna Hryniewicz: It's a disease that belongs to the group of neurodegenerative diseases, in other words, in the course of which nerve cells - neurons are damaged. The nature of this disease is the deposition of an abnormal protein called beta-amyloid and tau protein in the brain structures, resulting in the formation of amyloid plaques (senile plaques) with secondary degenerative changes in the neuron itself, a significant reduction in brain volume and neurotransmitter disorders. These are pathogenetic mechanisms that underlie further symptoms associated with Alzheimer's disease.

### **When do we get sick?**

In general, the disease shows signs after the age of 65. The beginning is very tricky and imperceptible. For a long period of time, these symptoms can be dissimulated by both the patient and the environment. After some time, patients begin to realize that they have memory problems, because they forget names, places they visited, things they did or where they put the car keys. Then, the close ones often say: *don't worry, it also happens to us* and they downplay the issue. And the disease process in the brain has already started - frequently few years before the onset of the first symptoms.

### **What is the course of the disease?**

It starts with memory loss, impoverishment of vocabulary. First of all, patients start to forget recent events with relatively efficient memory regarding the distant past. Problems coming up

with the right word or name and gradual impoverishment of vocabulary are early symptoms. There are also disturbances in spatial orientation, concentration and attention, reversal of the circadian rhythm of sleep and wakefulness. In more advanced cases, we can observe delusions and hallucinations associated with the state of threat from other people - often guardians. The patient has the impression that someone deliberately hides objects from them, robs them, tries to poison them. This in turn is a source of fear and anxiety. It is very upsetting and frustrating for both the patient and the family. Alzheimer's dementia is a terrible disease that deprives people of their identities - they gradually cease to identify themselves and their surroundings. Standing in front of the mirror, they see a stranger. The next stages of the disease lead inevitably to further degradation - patients stop talking, only make simple sounds. Also basic motor functions, such as self-eating, sitting or walking deteriorate. Eventually, the patients are completely confined to bed and depending on others. There is no contact with them, they require 24-hour care and supervision.

### **How to help such a patient? Is it even possible?**

Certainly, you can help to some extent, nonetheless there is no effective drug for Alzheimer's disease that would solve the problem. Early diagnostics is very important, because it gives a chance to extend the period of mild symptoms and independent functioning with the use of available pharmacotherapy. Drugs registered in Poland work symptomatically, but they do not affect the degenerative process itself. The disease progresses at different speeds and at the subsequent stages of the disease the pace of this progress may be different - months, years. It is an individual matter. A common problem in Alzheimer's patients is a psychological health disorder - initially mostly depressive disorder, then agitation, anxiety and hallucinations - and here medicine provides some possibilities of symptomatic treatment. Pharmaceutical companies are constantly trying to find a drug that would work not only on symptoms, but also on the cause of the disease and it is possible that in a year, two or three such cure will be found - intensive research in this field is going on.

### **You are also conducting specialist examinations at the clinic in Plewiska ...**

Yes. Our patients are involved in clinical trials with such drugs whose mechanism of action is directed at the cause of the disease - i.e. at the deposition of abnormal protein in the brain. We have been conducting one of the trials since 2016. Patients' observation lasts almost two years now and I must say that our observations give hope for a better future, also for other patients. In the very near future, we have a study planned for patients diagnosed with Alzheimer's dementia who have high levels of agitation and do not respond to standard treatment. We will focus on giving them peace, this is also important for the caregivers of such patients.

**But unfortunately, Alzheimer's disease leads to death.**

Unfortunately yes.

**What is the duration of the disease?**

It depends. The disease lasts between 4-8, sometimes even 10 years. A lot depends on patient care and how early the condition was detected.

**What to do when the patient needs 24-hour care?**

If we cannot take care of such patient ourselves - and this is often the case due to the fact that at some stage the patient requires 24-hour supervision - ask the appropriate institution. The first line of help is a family doctor or specialist who provides general medical treatment for the patient, from whom the family will get the first tips on what actions to take to protect the patient with proper, professional care. Such people absolutely can't be left alone. If the patient is at such stage of the disease that is no longer able to decide for themselves, the process of incapacitation should be carried out. Then, the legal guardian may place the patient in a specialized facility. If the family or guardians are determined to take care of the patient at home, they can also ask MOPS (Social Welfare Center) or MOPR (Municipal Center for Family Support) for help and support in this difficult and very demanding time. Remembering the purely physical side of care, I must stress, however, that the spiritual dimension of such care is of great importance - so that the patient can feel warmth and care - because we never know what level of feeling the person preserves. We must remember that sometimes mental suffering is more severe than physical .