

Matěj's story

Imagine you have a three-year old cheerful, healthy boy who likes to play and is full of life. And then, in one second, you lose him. What's worse, you lose him only partially. He is here with you, yet at the same time he is gone. He has been in a coma for almost 7 years and no one knows what he is able to perceive, what he needs or what he wants to say; you don't know if he feels your kisses and caresses. Matěj just had a trivial tonsillectomy and hospitals sometimes make mistakes, they say...



What does caring for Matěj look like?

Matěj needs permanent care 24 hours a day. He has food, liquids and medication administered into his stomach through feeding tubes during the day. He needs his body positioned and exercised and his arms and legs massaged. Aspirating mucus from his throat is of life-sustaining importance and must be done during the day as well as during the night. His vital functions are monitored 24 hours a day. Yet, his mom can "only" care for him 8 hours a day, seven days a week, because the parents also take care of Matěj's newborn brother. For the rest of the time, they hire professional nurses. Matěj's dad takes care of organizing everything around his son's care.

Why is Matěj at home? First, he is his parents' son. Also, almost no one knows what the real options for help from the state are.

Hospitals say: "Matěj is stabilized, there is no way of treating him, take him home."

Specialized facilities say: "We are really sorry but we only take on adult patients" or "We are really sorry, but Matěj has a tracheotomy, both of his hip joints are dislocated and some of the bones in his skull were removed, we couldn't take good care of him."

Hospices say: "We are really sorry but Matěj is not at the end of his life, which is not in line with our mission as a hospice."

What does and doesn't the insurance company pay for?

For three hours a day, Matěj is in the care of a nurse covered by insurance. His mom dedicates eight hours to him. For the remaining thirteen hours, the parents are apparently not entitled to any coverage by insurance, so they hire and pay for professional nurses. Together with supplementary payments for medical aids, the cost of Matěj's care reaches three times the average Czech salary, which is far outside his parents' means.

It is both the incident and the institutions' attitude to it that are tragic:

The hospital has not accepted responsibility and refuses to use its insurance, from which Matěj's costly care could be covered. The parents are suing the hospital in court. Last year the court ruled in their favour, but the hospital appealed against the decision. This means that the damages have not been paid yet and the court case will drag on for years to come.

The health insurance company and social security system both claim they cannot do more because Matěj doesn't fit into any of their categories. Therefore, his life remains in the hands of kind donors.

Matěj's parents and the NGO dedicated to helping him thank you for your support.

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