

ADDITIONAL ADVICE ON ALS LIFE'S END

For pALS with whom from research shows the disease is progressing very quickly it's of great importance that the caregiving is expanded sufficiently. In an early stage it's desired to draw up a plan with a social worker for home care help divided in packages, which doesn't necessarily only include a nursing help. When the disease evolves quickly there is great danger for exhaustion due to a constant lack of sleep, suffered by pALS as well as the home caregiver. In that stage a good plan, which was kept to a minimum at first, could be implemented more intensively. This is to avoid the sudden implementation of an emergency plan which could possibly fail to turn around the emergency situation. The perfect provided diverse caregiving contains nursing help of course, but also a cleaning aid and possibly another kind of assistance. The goal of the plan is to eventually make sure the pALS can stay in their own home with all the necessary comfort and support.

You also need to make clear decisions about the life's end of the pALS when they still find themselves in a non-critical stage. Some doctors feel uncomfortable talking about the death of their patient and the possibilities pALS and their families have to decide about the life's end ahead of time. Often they need a listening ear that

can also give appropriate advice. Specialized doctors can help, as well as home care nursing services and perhaps others such as palliative care.

When it comes to ALS the cause of death is often lung failure. The disease affects the respiratory muscles or the diaphragm. Some pALS's diaphragm is affected in an early stage of the disease, but this often happens later on. The cause of death of pALS is usually difficult to allocate because it depends on which muscles have been affected by the disease. If the most important respiratory muscles are damaged then the pALS will get more and more respiratory ailments and can eventually die from it. Breathlessness is a big burden but there is medication for it and there are other ways to keep the situation under control, and then there is also the possibility of artificial respiration. pALS who have swallow and bulbar issues can get pneumonia or other fatal respiratory problems. Especially when they choose not to be treated or in case the treatment doesn't work. The doctor who knows the pattern of the pALS's disease can answer specific questions about problems that are connected to breathing.

Translation: **Sara De Roy**