

## **Project Description HILDE UMDASCH HAUS**

Hearing the terrible diagnosis that a child suffers from a life-limiting or life-threatening diagnosis means a global change to the family's life. The idea of the house began with the mobile care of children and adolescents in need of care through Malteser Care-Ring. This service is provided since 2011 in Vienna and Lower Austria. Parents often reached the limit of their capacity and they wish to bring their child into a care-centre on a weekly base. To have some spare time for themselves or the siblings, who often get missed out. That got noticeable in the conversations.

The successful realised project HILDE UMDASCH HAUS (HUH) implemented for the first time in Austria a completely new concept of care. It is named after its donor Hilde Umdasch, a successful Austrian entrepreneur and supporter of the Sovereign Military Order of Malta. The house finally opened in autumn 2015 and offers a care unit for ten children, adolescents and young adults with a life-threatening diagnosis and complexity of medical conditions in need for special care. The HILDE UMDASCH HAUS is a place of safety, tranquillity, dignity but above all, a place of life.

The expert driven estimation showed that there are between 1.700 and 2.550 children and adolescents with life-limiting or life-threatening diseases in Austria. Although there is a range of providers offering mobile home-care there are no global respite services for caring relatives. In most cases the only opportunity given was to stay in hospital as an in-patient. That is the reason why we opened the HILDE UMDASCH HAUS with services of respite care, long-term care, end-of-life care and care in times of crisis. Last-mentioned service is for families, if a caring family member gets sick and there is no other person that can care for the seriously ill child. So we help families in a fast and easy way and help to avoid an unpleasant hospital stay.

Short-term care is not just a respite for the parents. It is also a good time for children, like they are on vacation and through the support of the pedagogical teams they enjoy a varied time. This house also got home for some children who moved in for long-term care. They live their daily routine in a shared house, visit the school in Amstetten and make friends with others in the neighbourhood.

The project follows a new approach concerning the caring concept. There should be no atmosphere of hospitals or nursing homes, but an atmosphere like it is in a shared house. Living together, the main idea was to avoid a hospital stay for children and to offer parents and families a break from the nonstop care at home. If there are no acute medical indications and the children are no longer benefitting from an acute care hospital yet are not able to be cared for at home, the HUH is the perfect place to be cared for.

One of the special features of the house are the two separated housing units for the parents, siblings or other relatives. They can be used if the parents want to stay with their beloved ones during some time of their stay at the HUH. They are often used when it is the kid's first stay in the house.

We want to empower the families and their children to lead a normal life despite all the circumstances that their sickness brings with it. One can also see the normal life in our daily routines, we use "normal wording" (e.g. move-in) instead of "hospital wording" (e. g. admission). Close cooperation between the nursing and the pedagogic team is essential for the success. The biopsychosocial dimensions are far more important than the medical diagnosis. Every single kid is supported individually according to its needs, therapy offers such as animal-, physio- and occupational therapy and logopedics are organized. The therapists and the medical team visit our home regularly.

The capacity rose continuously after opening month per month and by the end of January 2017 finally all ten single rooms were occupied. This shows, that there is need and how important our offer is to the families. The inquiries from families with severely handicapped children and adolescents increased, who asked for short time support. Even though the diagnosis is not in any case palliative, as required for funding by the board of ministry, we want to support them. In the first months we opened the institution for those families, although there was no public funding to cover the costs of the stay. We had the capacity, so we supported those families.

We are happy, that our institution has found its place in Amstetten. On the one hand we provide interdisciplinary, best professionally care for the children and adolescents. But on the other hand we undertake the special social task of drawing the society's attention to the offers of best care for those children as well as information services. We have an open house and many guests are visiting. Diverse projects take place in cooperation with the schools, companies and clubs. They contact us because they want to donate money of their events. The creativity is one-of-a-kind. We want people, who never had contact to critically ill children and adolescents, to experience what it means for a family to take care of such a child and to appreciate their efforts.

For the future we want all families with children and adolescents with a life-limiting/ -threatening diagnosis to know about the HUH, to choose whether they want to make use of our offers or not. Through networking with cooperation partners and other service providers we are on the right way.

Public funding from authorities in Lower Austria and Vienna help to cover the costs. Donations help to finance therapies for the children and adolescents. Due to the geographical proximity we wish to get public funding also for Upper Austrian children – why there is no public funding for children if they live 20 kilometres north?