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The enjoyment of life in a childhood curtailed

PERSONAL EXPERIENCES

ANONYMOUS

The author wishes to remain anonymous, but their identity is known to the editors.

Our daughter's greatest desire was to live normally – in the days she had left.

Our ten-year-old daughter marches through the main entrance of Oslo University Hospital while her parents run after this strong-minded child. She is one of 4–5 children annually who are diagnosed with diffuse intrinsic pontine glioma (DIPG) in Norway, a lethal brain tumour. Our daughter envisions a future of 9–24 months, a time frame in which all the family members, all the pupils in her class and dance group are present and where life is to be lived to the full. The hope of an incorrect diagnosis lasts until she dies at home,13 months after receiving the diagnosis. What did we learn during this year spent consulting hospital doctors, nurses, paramedics, physiotherapists, occupational therapists, social workers, psychologists, pharmacists, assistive technicians, music educators and teachers?

What is quality of life?

When the DIPG diagnosis was presented to us parents, we experienced a feeling of paralysis. Only our eyelids blinked to send SOS messages to the outside world. However, the power to act quickly returned. We decided to give our youngest daughter a good life, in the days she had left. Quality of life is defined as satisfaction and enjoyment of life and finding meaning in what we do (1). What does this mean for a ten-year-old child? Friends, school, leisure activities, siblings and street games, even homework, represent quality of life when you are ten years old. Our daughter's greatest wish was to avoid hospital and live at home. We wanted to fulfil that dream of hers. We would stay together as a family, be at home and promote quality and enjoyment of life.

We agreed on this, but were nevertheless left with many questions. How to ensure quality of life for a terminally ill child, in a family of several children? At what point should one deprive the sick child of the hope of better health or a long life? Does quality of life increase by travelling abroad to seek treatment? What about her siblings? As parents, should we deprive her siblings of the opportunity to be close to her in the final phase of life? When will the final phase of life come? How honest should you be regarding the cancer and prognosis with close family and friends? What about the school, friends and teachers?

How much cancer and death can a local community endure?

Too many tests?

In the healthcare system, the focus is on reduction of bed-days, good patient care progress, guidelines on prioritisation, communication with the patient and next of kin, research and professional guidelines. What about quality and enjoyment of life in the midst of all this? Will a properly assessed MRI result in a better life? Medically, yes, because it provides treatment options, but perhaps not from a human standpoint. How to ensure the right decisions? In my opinion, therapists ought to review all clinical procedures and actually ask themselves: Is this necessary? Our experience was that many of the blood tests, medical examinations and periods of hospitalisation could have been avoided.

As parents of a sick child, we had to insist that medical tests were performed at the local hospital. It seemed a waste of time to drive for 3–4 hours to take a blood test, give intravenous medication or flush a venous catheter when the same procedures and patient care are available locally, a car journey of 20 minutes.

> ***«Must all children who walk in the shadow of death have parents who fight like lions to ensure home-based care for as long as they want?»***

The child must use his or her energy on what brings them joy (2). Meetings and conversations with health professionals to establish an understanding of what experiences we wanted our daughter to have of the health system took a lot of energy. We worked hard to prevent her expending her strength on unnecessary encounters with healthcare personnel and spending time in hospitals.. As we found it was largely up to us to decide on the choice of treatment, and to obtain greater clarity regarding treatment options, we contacted oncologists in the USA who gave sound advice. We did not feel good about this. In the palliative phase, as parents, our confidence lay primarily with local doctors, the GP and the palliative care physician in our municipality as well as paediatricians at the nearest children's ward.

The question we have asked ourselves is: Do healthcare professionals prioritise other children's quality of life and desire to live in their local community? Do they dare to trust that local expertise can ease the everyday lives of terminally ill children and their families? Do all parents receive the following message from the local palliative specialist early in the disease trajectory: 'We are good at home-based care in our municipality – trust us, if and when that time comes!' Must all children who walk in the shadow of death have parents who fight like lions to ensure home-based care for as long as they wish, and that all hospitalisations and testing are made as simple as possible?

The final phase

Our daughter had few hospital stays. Her friends came to visit her at home, even when all her functions were significantly reduced. Family, friends and siblings experienced good teamwork by the local municipality, caring local doctors and assistive devices which were customised to the situation. All this enabled us to fulfil our daughters wish to remain at home until her very last breath.

Children's joy and laughter are the best medicine for exhausted parents. It is wearying to encounter health professionals who do not see solutions in collaboration, but only difficulties. We cry out with all our might, in grief, longing and despair that others fail to see the whole picture, only focusing on one piece of the puzzle; the diagnosis. Lift up your eyes, see the whole picture, fight for a good, local healthcare service that is best for our children! Until future research gives children with the diagnosis DIPG the title 'cancer survivor', we must focus on collaboration and teamwork to promote satisfaction and enjoyment of life.

LITERATURE

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