



## Documentary

### The fight against paediatric cancer

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#### How I Live

Directed by Meghan Shea

Persistent Productions, 2019

88 min

For more on the **documentary** see <https://www.howilivewithcancer.com>

Although childhood cancer is highly curable in high-income countries, 80% of children with cancer live in low-income and middle-income nations. *How I Live*, directed by Meghan Shea, offers an intimate look at global paediatric oncology from the perspective of not only the patient, but also their family members and health-care team. Filmed across five nations, the documentary candidly chronicles the journeys of four children and the struggles faced by their parents and health-care workers in overwhelmed cancer hospitals.

The story begins in Guatemala, where a 6-month-old girl named Keira and her parents travelled for 8 h to reach the National Pediatric Oncology Unit (UNOP) in Guatemala City. The family received donations from their entire village in order to finance the arduous journey across dangerous mountainous terrain. Keira was originally diagnosed with cataracts by her primary-care provider; a second opinion by a paediatric ophthalmologist suggested an ocular tumour, and Keira is now at UNOP to treat her retinoblastoma. Many developing countries have inadequate health education and early detection, meaning that late diagnosis of paediatric cancer is a major issue because of deficiencies in the public health sector and poor public awareness. In addition, low-income families often stop treatment prematurely after a few cycles, thinking that the cancer is cured or because of costs or logistical reasons.

In Myanmar, paediatric oncologist Tint Myo Hnin describes the plight of physicians in the nation. 80% of physicians in Myanmar are female because the monthly salary is roughly US\$250—“not enough to raise the entire family” in a place where men are seen as the “primary breadwinners”. There are fewer than five paediatric oncologists in Myanmar. Hospitals are “always understaffed” and physicians often migrate overseas for more lucrative offers. Patients usually present during critical stages and hospitals only see 10% of the possible newly diagnosed malignancies in Myanmar. At the Yangon Children’s Hospital in the country’s largest city, a 6-year-old Burmese girl named Shein presents with swelling

around her eye. Her family travelled for 3 days from the rural countryside to reach the hospital. Eventually diagnosed with non-Hodgkin’s lymphoma, her treatment drives the family into insurmountable debt because of transportation costs. Like Shein, most patients in the hospital rely on places of worship and charities for short-term housing while receiving treatment.

Although standard generic chemotherapy drugs are relatively inexpensive, accessibility remains a barrier for the poor. In addition, successful treatment requires proper medical infrastructure—such as having timely access to antibiotics, blood transfusions, and pharmacists who can properly prepare drugs—which is often lacking in developing countries. For example, in Ghana, childhood cancer is not covered under the national health-care plan because of budget constraints. At the Korle-Bu Teaching Hospital in Accra, improved training and collaboration with international organisations such as the International Society of Pediatric Oncology (SIOP) have drastically improved outcomes. New nurses are taught counselling techniques and provide parents and families with accurate health-related information about cancer treatment, side-effects, and psychosocial needs.

Central and Latin America are considered success stories in making progress. 20 years ago, paediatric cancer was considered a death sentence and children were often marked with a black cross. However, thanks to increased collaboration between health-care professionals and organisations such as the Central American Association for Pediatric Cancer and Hematological Diseases, the cure rate is now 60–70% for some cancers. In Guatemala, from 1990 to 1995, only one in six patients was diagnosed, 42% of children abandoned treatment, and only 20% were alive after 2 years. In 2017, UNOP saw 400 of 600 cases in Guatemala and the overall survival increased to 65%; treatment abandonment rate was reduced to less than 1% and therapy refusal to less than 3%. Despite these encouraging statistics, the documentary’s true strength lies in its profoundly empathetic and honest approach towards highlighting the triumphs and tragedies associated with paediatric cancer treatment. As a result, the resilience shown by the children, as well as their parents and caregivers, is truly inspirational.

Overall, *How I Live* is realistic and thought provoking, and it will hopefully spur policy makers, clinicians, and activists into action—by showing that through international collaboration and innovation, cancer treatment facilities can dramatically improve survival outcomes and inspire communities to tackle a once unbeatable foe.

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