

# PATIENT ADVOCACY in Uganda

SUBMITTED BY THE AMERICAN CANCER SOCIETY

UPON HEARING HER DIAGNOSIS OF CERVICAL CANCER, the world of 19-year-old Ugandan Kembabazi was shattered and her dream of acquiring a university degree put sharply on hold. As the oldest child of a single mother, the diagnosis came as a shock to the family and the once bright future her mother had anticipated for her, became instead a dim possibility. But it is not simply the disease the Kembabazi must battle, but at her young age she must also navigate the struggles associated with her late diagnosis, stigmatization of the disease, and treatment limitations in her country.

Kembabazi had enrolled at Nkumba University with the hopes of receiving a Bachelor's degree in Business studies when she began to exhibit symptoms such as stomach pains, fatigue, and rapid weight loss. As she did when Kembabazi was sick before, her mother took her to the clinic in their town. But doctors simply gave her pain killers and antibiotics and sent her on her way. However, after multiple visits, it became apparent that a deeper diagnosis was required and she was referred to Mulago hospital in Kampala and from there to the Cancer Institute for further testing. The results from the Cancer Institute came back conclusive for cervical cancer. The delay in Kembabazi's diagnosis came not only from limited medical facilities but lack of knowledge and awareness surrounding the disease. Had Kembabazi been diagnosed earlier, she would not have suffered as severely those early months, and would have been able to start her appropriate treatments at an earlier stage of the cancer. Due to the limited facilities of her local clinic, Kembabazi was instead forced to leave her family and make her way to a patient hostel in Kampala where she will stay until she completes her treatment.

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Being so young, receiving such a serious diagnosis, and having to travel so far away from her family, has a strong effect on Kembabazi's emotional state. The stigmatization that comes with a cervical cancer diagnosis is deeply ingrained in communities such as Kembabazi's and patients often find themselves isolated from their peers. Lack of education surrounding the disease and myths or inaccuracies contribute to this. To help with her emotional state during her treatments Kembabazi also sees a psychologist. According to the psychologist, since her diagnosis Kembabazi has become withdrawn and closed off from her friends, fearing the stigmatization associated with this disease. While she speaks fondly of the past, and how she had big plans for after graduation, the psychologist can't help but notice that she never speaks about the future. Isolated from her family due to the distance coupled with the withdrawal from her friends, the psychologist considers herself to be the only friend Kembabazi has now.

In addition to her emotional struggles, Kembabazi also faces difficulty with her treatments. Not only are there side effects, but although Kembabazi diligently shows up for her chemotherapy treatments at the Cancer Institute, sometimes she is forced to skip sessions because treatment drugs are out of stock. These drugs are more readily available at private hospitals, but the cost is so substantial that her mother is not able to afford to buy them. This limited access not only interrupts Kembabazi's treatment plan but undeniably causes her increased pain and anxiety surrounding the outcome of her disease.

What is so compelling about Kembabazi's story is not only how young she is to receive such a diagnosis, but how many hurdles she must face in her fight. She must navigate through her own treatments and emotional journey with such limited resources and support. Her story calls attention to how many aspects of this disease still need additional resources, additional funding, and additional education surrounding them to save, extend, and enrich the lives of cancer patients. Increased early detection tools and prevention are vital to ensure that girls Kembabazi's age do not suffer through a similar struggle when they have barely had a chance to start their life. In addition, better access to treatment therapies, increased education surrounding the disease, and more robust patient support systems all could have made Kembabazi's journey much less harrowing. With greater access and continuity of care comes the increased chance for survival and the chance for Kembabazi's mother to watch her oldest child win this battle and go on to fulfill her dreams.

