

Thank you for having me here and inviting me to speak about Adolescent and Young Adult Cancer. My name is Alec Kupelian, and long before I became the Program Development Manager at Teen Cancer America, I was diagnosed with a 19 centimeter long Ewings Sarcoma in my left hip.

I was in my first year at university, moved out from my parents' home for the first time, and trying to navigate what it means to be my own person in the world. I thought I pulled a muscle playing sports, but it never got better. My 'injury' grew worse by the day until I lost use of my left leg. On Sunday, May 18<sup>th</sup>, 2014, I got an MRI. Monday, I had my biopsy. Tuesday, I had my port emplaced. By Wednesday, I'd started chemotherapy. In those four days, I had to pack up my new independent life, say good-bye to my new friends, and move back in with my parents. I spent the next 11 months receiving the treatment that would save my life. It was during this time that I began advocating with Teen Cancer America.

I began advocating as a success case for AYA cancer, I was one of the ones that made it. I thought that because my scans showed 'no evidence of disease', that I was done with cancer. I wasn't. Not because my cancer ever came back, but because the entirety of having cancer affects so much more than just whether or not I still have cancer.

Physically, I had to relearn to use my left leg which had atrophied down to nothing, I had a series of mini-heart attacks when I exercised (which I had to do to strengthen my heart), and to this day I still suffer peripheral neuropathy. And that's just some of the physical side effects. Not to mention all the psychological, neurocognitive, and interpersonal challenges I had throughout my treatment through until today.

Since my own diagnosis 9 years ago, I have been experiencing the unique challenges of AYA cancer patients first-hand. I began to do advocacy work with Teen Cancer America during my treatment and have been employed by them full time in a program development role for the last four years. This work is my life, my passion, and my experience.

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By the end of my talk today, I want everyone in this room to understand why AYA oncology is different than early pediatric and late adult oncology, and what we are working towards in the United States. I am going to present AYA as a disease agnostic group, defined by their age and their place in life, rather than by their characteristic diseases. I'd like to split my talk into three sections: Why is it important to treat the AYA-population as distinct, how can we approach AYA-specific care, and what tangible steps we can take to build AYA specific programming.

For the rest of this presentation, when I talk about AYAs, I am referring to the 15-39 age range. Although definitions for AYA do vary a little around the world, this is the generally accepted definition and how most data for this presentation was pulled.

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So what makes the AYA population unique? Cancer, unfortunately, doesn't discriminate by age. We are seeing not only a growing population of young cancer patients, but also the changing epidemiology of these AYA patients. The reason AYA is defined as 15-39 is that there is a drop-off in the rate of improvement for loss of life and disability years of life compared to younger and older patients. This means that the AYA patients are not benefitting from the advances in modern healthcare to the same degree.

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There are more than 1.3 million cases of AYA cancer being diagnosed from around the world. This heat map shows that the incidence of AYA cancer is growing, every where. There are many explanations as to why this could be case. The global population is increasing, screening is becoming better and more accessible, and changes in our diets and environment could be increasing the prevalence of the disease. This further illustrates that these patients need to be acknowledged and taken care of.

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Cancer is the 4<sup>th</sup> leading cause of death for young adults around the world. There are almost 400,000 AYA deaths due to cancer each year. Cancer is quite literally taking the future of our youth during their adolescence. It ranks higher than heart disease in high income countries like the United States and Chile. And these figures only illustrate mortality, however we also know that young adult patients are the most likely to be non-adherent to treatment, be misdiagnosed and late diagnosed, and not have an available clinical trial. If all of that wasn't enough to demonstrate that AYAs need dedicated effort for equitable care...

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Consider this age range in absence of cancer. These are just some of the issues and challenges AYAs face in their lives. Cancer complicates each and every one of these.

The AYA age range is very broad. Picture yourselves at 15. Now imagine that you lost all of your hair, had scarring from surgery and couldn't go to school alongside your peers because of treatment. Imagine yourself

in your early 20s trying to work your way through university or starting your first careers, finding long term relationships and maybe getting married. Imagine getting cancer whilst pregnant or with a small child. How were your finances during those times in your life? How much does it cost to even get to the hospital to receive treatment? Even if treatments are covered, cancer is expensive. I have spoken to a young father, diagnosed with a treatable cancer had to make the choice of receiving treatment or feeding his family. I have spoken to the 27 year old girl who finds out she cannot have her children because of her cancer treatment 10 years prior. I have been the 21 year old college student who attempts suicide a year after I'm declared in remission because I couldn't contend with my own depression.

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These stories are not the exceptions. A study that came out earlier this month from Poland found that risk of suicide for AYAs after a cancer diagnosis is 2.39 times higher for AYAs than in the general population.

Everyone's story is a little different but the needs of AYAs are consistent. Which is why we need to consider this population as a unique age group. This isn't only a pediatric or an adult problem. The solution can't come from only pediatric or adult centers. There must be collaboration to care for these patients who sit in the middle ground.

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At Teen Cancer America, we have modified the NCCN Guidelines to create these eight pillars of care. AYA Oncology programs are developed in collaboration between pediatric and medical oncology. They coordinate and build upon existing services and resources to:

- holistically assess and address the unique physical, emotional, and psychosocial needs over time of adolescents and young adults who have been diagnosed with cancer,
- and educate and support the providers caring for them.

Age-appropriate care requires communication between the representative disease teams to confirm the best course of treatment. In the US, leukemia patients on the pediatric protocols have 25% better outcomes than those, of the same age with the same disease, on the adult protocol. The reverse is true for colorectal patients, if the pediatric facility will see them at all. Often, AYAs diagnosed with cancer never see someone their own age with cancer. Creating an environment that is welcoming to AYAs and allows them to connect with peers helps them not feel so alone at a time when they already feel so isolated from their peers.

How do we create trials whose catchment includes patients that are in peds and adult oncology? How do we make sure that every patient diagnosed has the conversation about how treatment can affect their fertility and the opportunity to preserve their fertility where medically possible? ...

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How can we get supportive care services to these patients that help manage all the added complications to their lives that cancer brings so that we are treating the whole person with cancer, and not just the cancer itself? Our patients are people first, and cancer doesn't only affect their physical health. And those needs change over time, well past the end of treatment or even the 5 year mark. The latest data of the Global Burden of Disease report I used earlier showcases that a majority of AYA patients end up with an average of 5 cancer related

morbidities or disabilities at 15 years past their diagnosis. The end of treatment cannot be the end of care because the effects of treatment last well beyond the end of treatment.

This figure showcases a patient pathway of care through the hospital. Regardless of whether an AYA patient enters through the doors at a pediatric or adult facility, after diagnosis we'd like them to receive some form of all these resources before they even begin treatment. Patients should be regularly screened to flag and address patient needs and concerns. When I talk about an AYA program, this is what I mean. It is the consolidated list of resources and services that all AYA patients can gain structured access to throughout their treatment and survivorship which address their holistic needs.

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That's a lot. I know that what I'm asking for is a lot for both the healthcare system as a whole and the individual providers within it. It's overwhelming, and I am not blind to that.

Clinicians, as I'm sure *you all* know first hand, are very busy people. Which means when we consider how to implement these programs, we also have to acknowledge the people who are providing that care. When we talk about Program Implementation at Teen Cancer America, the first piece of advice we always give hospitals is Slow Down. You don't have to do everything, all at once. What's important is to have the end goal in mind, and work step by step to get there.

In order to implement these programs, we need to understand our patients' needs and then understand our healthcare systems.

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The only way we can know is to ask. And that thought is central to AYA programming. Engage your AYA patients in building programs for them. Use their voices, many of them want to be heard. In the US, we have groups of AYA patients and survivors create advisory groups to help advocate and guide initiatives within a hospital or health system.

Additionally, in order to link patients to the right resources, we must understand their personal needs. No two patients are exactly alike and each individual patient's needs change over time. These supportive care screenings are one way you can ask your patients about their needs in a way that you can, ideally, track in their medical records. This is one example of a screening called the Needs Assessment and Service Bridge that we encourage programs to use, but there are any number of options that work.

Once a patient indicates what their needs or concerns are, their healthcare team needs a manageable way to link patients to resources or services that address their specific concerns. These can be done through automatic or manual referral pathways, patient navigators, or even just an informal introduction to an outside resource that the patient can reach out to.

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Just because I know the words are tiny on the screen, I've included the titles of each of the sections of NA-SB here. The creators of NA-SB are very open about its use so I am happy to share with anyone who is interested. Just as we've talked about how patient needs change over time, we encourage hospitals in the US that use these screenings to give them to their patients every 2-6 months.

Basically, every 2-6 months you have a patient fill this form out in person or digitally, and they indicate whether they'd like more

information in an area, have enough information, or not applicable. For anything the patient indicates they need more information on, the goal is to connect them with an internal or external resource which would provide that support.

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It's very easy for me to stand on this stage and say, just do everything. It takes dedicated time and effort to build these programs out. Time and effort that clinicians often don't have. In the United States, we don't have a national healthcare system so we work with each individual hospital on creating a unique program to fit their institution. At Teen Cancer America, we've spent the last 10 years providing the conceptual framework through an evidence-based approach that gives the healthcare providers who are trying to do better for these patients the expertise needed to build something comprehensive.

In addition to understanding patient needs, we have to adequately understand our own systems before we can make change. Are your AYAs being treated in-patient or out-patient, peds or adult. The country of Chile is very long, and much like the United States, some patients often need to travel hours to get to a major hospital. You must know where your AYAs are, before you can reach them.

Then figure out what already exists. These can be services that exist in your institution, but these resources can also come from NGOs and organizations. There is a peer support program called Immerman's Angels which does international peer to peer mentoring. This is where those informal introductions are key. Or maybe your hospital doesn't have the capacity to do fertility preservation. Are there local clinics you can refer your patients into? And accessing those digital service lines



are great! What can you provide to your patients that are hours away from your hospital so they can still access the support they need.

For the services that patients don't currently have access to, how can you fill that need? If your institution doesn't have the bandwidth to provide a service, find out who does. Maybe there are service lines in the system that aren't oncological that are relevant or maybe you will have to hire a new staff member to fill that need. Maybe it's a service that doesn't exist at all yet. If that's the case, creating a service line from scratch is daunting, but we have models of care from the United States we can share as well so you don't start from nothing. My hope is that in collaboration, we too will learn from the way you run your healthcare system that we can bring back to our own hospitals.

But for each service, whether it exists or needs to be added, I want you to answer consider these questions. How do patients access this resource? How can we better that access?

How do providers give patients that access? Can we make it easier for them? Let's be honest, if it is going to be challenging or time consuming, a lot of times that means it simply won't get done. Which isn't a criticism, it's a reality. Clinicians do not have a lot of spare time, and we don't want to overburden our providers more than they already are. So how can we make these processes easier on them day to day?

And how much is providing this service going to cost? What is the cost to the patient and the health system? It is easy to speak about creating new service lines in a vacuum. But the reality is each of these services is going to cost money. How much does it cost is an unfortunate reality to healthcare that we also can't ignore.

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In summary, AYAs are a unique population with unique needs. We must consider the whole patient in order to adequately treat them. It is important to understand both your patient's needs and your health system. Just last week, Teen Cancer America hosted the 5<sup>th</sup> Global AYA Cancer Congress in Long Beach CA. So I do understand the tremendous effort and stress you have all gone through to put on this amazing congress here. I don't bring that up just to brag, although I am proud, but to say that we were able to get AYAs from around the world into one room to talk together about their experiences, to learn from each other. Not all experiences were negative either. But the overwhelming theme throughout that side meeting and Global Congress as a whole was to bring in the AYA voice. I was part of the closing speech for Global Congress so I asked a few other AYAs what they wanted people to leave Global Congress with. I'd like to share this quote from a young woman named Christina Best.

“Both professionals and AYAs are hungry for more collaboration and inclusive spaces to improve the experiences and outcomes at all phases of health and living. Take time when you get back to your homes to process and plan for the next steps. Find ways to include and elevate AYAs across backgrounds in this work. Find ways to bring them to your meetings. When you cannot find a way, make a way.” I challenge each of you to consider how you can better take care of your adolescents and young adults. No one individually is going to be able to provide comprehensive care alone. So decide, right now, what is it you can do within your sphere of influence to better their care. Send an email to someone you can collaborate with, get someone's email here that you don't know, that will do the same. You work in healthcare because you want to take care of your communities. If you can't find a way, make a way.

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