

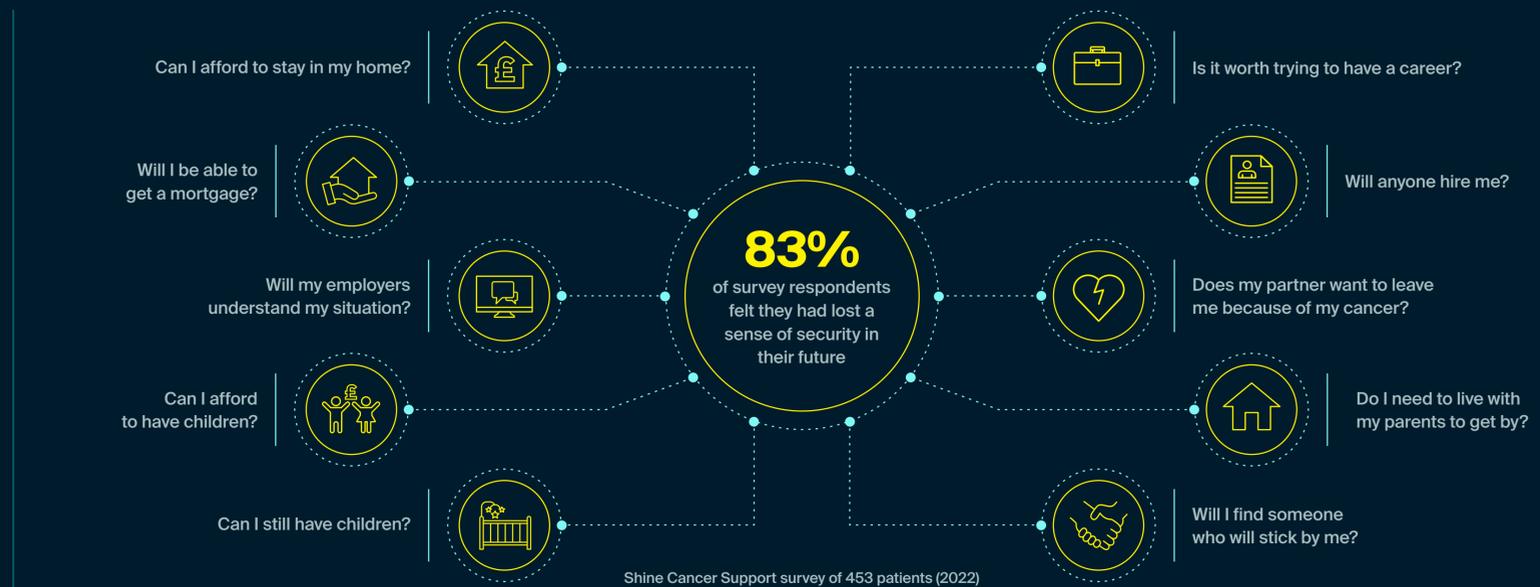
'Shining' a light on young adults with cancer: how a cancer diagnosis and uncertainty creates special challenges for this age group



Ceinwen Giles

Co-CEO at Shine Cancer Support
Cancer survivor
Lumanity Expert Patient Council

We sat down with Ceinwen Giles – Co-CEO of Shine Cancer Support, a patient-led cancer organization, and a member of the Lumanity Expert Patient Council – to talk about the special challenges facing the young adult cancer community. While a cancer diagnosis at any age is potentially life-changing, young adults face specific challenges given this is often a 'building' time of their life in terms of things like employment and relationships. Here we share how Ceinwen and Shine are helping this community and what more needs to be done to support these patients at such a critical time in their lives.



Q&A



➔ Please introduce yourself and give us a brief history of your organization?

My name is Ceinwen Giles, and I'm one of the co-CEOs at Shine Cancer Support, a charity that focuses on the "younger adult" cancer population. We exist to fill a gap in mainstream cancer services. Broadly speaking, a lot of the focus on cancer support services focuses on the needs of middle-aged to older adults, and, of course, there are specific, dedicated support services for pediatrics and young adults, but, for those in their 20s, 30s, and 40s, it's really tough to find information and support specifically for the needs that you might have at that stage in your life, particularly when you are repeatedly told that you are "too young to get cancer".

Our organization is entirely patient-led; all our employees, including myself, have had cancer, and all but one of our trustees have had cancer as well. When we started Shine, we didn't feel the existing support groups were tailored to our target age group, and they were often led by a medical professional and occurred in hospitals or in venues that didn't encourage social engagement. As co-founders, we both felt, "I want to just go for a drink or coffee with someone who understands my life situation and have a chat." So, that was where we started about 11 years ago, just seeing if anyone wanted to come out for a drink. And we were really pleased to see that a lot of people wanted to.

➔ How would you define your organization's purpose?

We aim to inform people by sharing good quality information around the issues and topics that are affecting them at this particular time in their life. For this age group, it includes things like fertility and family planning, mental health, returning to work, and living with cancer long-term. We try to influence policymakers to understand that these are important issues that have a huge impact on quality of life for this demographic. Fertility is a good example – ensuring that people realize they need to have this conversation at both the beginning and end of their treatment. We give them the tools to go back to their doctors and say, "Actually, I've got questions; I would like some tests," that kind of thing. Patients need to be empowered to understand all their options.

Perhaps most importantly, we try to connect patients. We're constantly trying to expand our reach so that we reach more of the people diagnosed every year in this demographic. Being patient-led has really made our services more meaningful, more exciting, and more applicable to the needs of young adults with cancer. We operate through volunteers who are mostly younger adults who've had cancer themselves or might be living with cancer. We don't provide cancer-specific information because we're a pan-cancer organization; we'll support anyone with any type of cancer at any stage. If someone has a cancer-specific need, we refer them to a partner charity. We also provide training for healthcare professionals around the needs of young adults with cancer and hope that they'll tell their patients about us.

➔ What are the biggest challenges your members face?

If you think about people in their 20s, 30s, and even into their 40s, they tend to be at the start of, or building, their career. They might be dating or recently partnered and thinking about having a family. The realities and emotions associated with this differ to older cancer patients who may have a long-term partner; they've had children, a career, and may be facing retirement and likely have a different support system in place. The concerns for both groups are important, just really very different. If you are 30 and receive a cancer diagnosis, it's hugely disruptive to both your immediate and longer-term life plans. A 30-year-old is potentially facing a longer future living with the impact of cancer than a 60-year-old. If cancer impacts your ability to work full-time, it's not just a short-term issue where you might be able to choose early retirement. If you can't work full-time, it's not just something that affects you at 30 or 40, but for the rest of your life and can affect your employment options and ability to get a mortgage and look after your family.

To add to this, a lot of the concern can manifest itself in rates of anxiety, depression, and feelings of uncertainty. We know that rates of loneliness and isolation are high in this age group, and so our outreach and peer support is fundamental to what we do. We run a mixture of online and in-person programs and work with nurses and psychologists as well as doctors to make sure that the advice and psychosocial support we offer is evidence-based.

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➔ How well does the pharmaceutical industry understand the challenges your members face? Is the pharmaceutical industry helping you address your challenges?

I think there's a growing awareness across the industry of the psychological impact of a cancer diagnosis. There is definitely more focus on mental health, and I think the pandemic has helped with awareness for this. One overlooked aspect is how hard and unsettling it is to have to live with uncertainty. There's good research to suggest that if you are certain something bad is going to happen, that is actually less upsetting than being uncertain about the outcome. We work with people to make them understand that one of the reasons they may be feeling so awful, particularly for this age group, is the level of uncertainty around their disease and their future. I don't think the industry, or society, understand that fully.

I think the pharmaceutical industry has learnt a lot from patients, especially with respect to their role once treatment ends. This is often when the emotional impact of a cancer diagnosis hits because there is an expectation that things will return to "normal" following treatment, but this is not always the case. We are seeing a lot of this age group falling into a post-treatment "void". I think there is a lot more that that could be done in partnership with the pharmaceutical industry to address this and perhaps develop some services.

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➔ What more could be done for patients in your view?

I would love to see more training for medical professionals around the psychological impact of cancer for this age group and enable them to understand the critical conversations they should be having with their patients. Very often medical professionals are rushed. They ask the patient how they are, and the answer is often, "Yeah, I'm okay." And that's it, end of conversation. Ideally, they would be encouraged to take a few more minutes to sit down and unpick how people are feeling and why they might be feeling that way. And when considering treatment, not just focusing on outcomes like extending life with an incurable diagnosis, but thinking about what the emotional impact of that diagnosis might be, because we have a growing cohort of patients who are living longer with cancer. This has almost created new issues in terms of how you cope psychologically with the fact that you are actively living with cancer, and you don't know what that looks like. There is a lot more space to think about joining up the physical and the mental health of the patients that they're targeting.

We know quite a lot generally about what happens to cancer patients and how people adjust, but it's not age-specific. We did a survey in 2019 with this demographic and it showed that 83% of the people that answered the survey had lost a sense of security in their future. That's a huge number and a really unfortunate situation. It also suggests that we are not doing enough with this age group to understand why they feel this way and what can be done to support them.

➔ If you could change one thing to benefit your membership and reflect their needs, what would it be?

It would simply be a plea to see this group as unique. They've moved out of their childhood home, most of them are independent, they're working, they're starting families. And their needs really do differ to much younger and much older people. I would love for anyone reading this to come away with an understanding that this is a group of people that does have distinct needs, and they need to be supported in different ways. Loneliness, isolation, depression, and anxiety are very real for this group because they're very often the first people in their friendship group that have had a cancer diagnosis, so they won't often know anyone their own age who's had cancer. I think there's just a lot more all of us – healthcare teams, the industry, advocacy groups, and society – could be doing to support them and to make sure that they're connected with one another and feel better about their futures.

Ceinwen Giles is a Co-CEO at Shine Cancer Support, a national charity supporting adults in their 20s, 30s, and 40s with cancer. She has extensive experience in the charity sector, both in the UK and internationally and, before joining Shine, worked in the field of international development, where her clients included large non-governmental organizations, the United Nations, and the Department for International Development.

Ceinwen was diagnosed with stage IV non-Hodgkin lymphoma six weeks after her daughter was born prematurely. As a result of her cancer treatment, she developed a chronic immuno-deficiency condition. It was this experience that developed her interest in patient involvement in the UK's healthcare system. In addition to her work with Shine, Ceinwen is the Chair of the Patient and Public Voices Forum of the NHS England Cancer Programme, a member of the General Advisory Council of The King's Fund, and sits on the BMJ Patient Partnership Panel. She is also a mentor for fellows of the YearHere program which develops social entrepreneurship skills among young adults.