



a survivor's story



From the Australian Cancer Survivorship Centre



Alexis Kolsky's story, as told by Meg Rynderman, a consumer representative for the Australian Cancer Survivorship Centre

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'Can't run, can't jump, can't ski' Alexis Kolsky

Exams or x-rays, study or scans, university or ultrasounds, cocktail parties or chemotherapy, holidays or hip replacement – these are not the everyday choices facing a 17 year old. Alexis Kolsky was confronted with them when she was diagnosed with Ewing sarcoma, a rare bone cancer, during her VCE exams, just over four years ago.

I met Alexis recently and listened to her story. She is a bright, bubbly 21-year-old university student; we fitted our meeting in between her university lectures and work commitments.

Alexis had noticed a lump on her thigh but ignored it. "I thought I'll get through VCE [Victorian Certificate of Education] first and then I'll deal with that later."

She finished her exams, told her Mum about the lump on her leg and what followed was a speedy round of doctors visits, tests and scans.

"I kind of got raced around to different hospitals. I had to go to one hospital and get MRIs done in emergency and it was a big race around until my GP referred me here [Peter Mac]. This was all within a span of about three weeks."

In the soft tissue of her thigh, her doctors discovered a 14 cm tumour, which had originated in the femur.

The whirl of testing and the immediacy of treatment left Alexis numb.

"I didn't really deal with the emotions. There wasn't really time to sit back and go, 'Oh God'. It was kind of, 'Okay, you've got to do this now and then you've got to do that'. It was so busy. And always the tests. They're scary: huge machines revolving around you and I was just terrified of all that. So I didn't have time to be scared of the actual cancer."

Alexis was concerned for her parents, sister, extended family and friends, feeling that she needed to be strong for them.

"I was worried about the people around me getting worried or upset. I didn't even want to cry when they first told me. I was trying to hold it in. The other people around me were crying about it, but I'm not. I just tried to keep making jokes of things, like my hair was quite long but quite damaged from colouring and all that and I'm like: 'Well, it's probably good, I'll get a fresh start' – trying to make a joke or make a positive out of everything."

Fourteen rounds of chemotherapy every three weeks, interspersed with hospital admissions for tonsillitis, fevers and colds, were followed by hip

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replacement surgery and a slow, painful rehabilitation.

Alexis had been a healthy active teenager, involved in sports.

"It meant I can't go back to dancing, can't run, can't jump, can't ski, anything fun you can't do. I just realised how much I was missing out on. My friends were starting uni, they were meeting all these new people and there I was stuck in a hospital bed on a Saturday night.

"I think when you're older, it's easier. You know, if they say to you at 60, 'Well you can't run or jump' – 'Well, that's good – I don't really want to!'"

Alexis recalls being confronted with her body's rapid response to her chemo and reflects on the support she received from her family and friends.

"I became really needy during it – I just didn't want to be alone a lot of the time, so Mum would be at my bedside almost all day and half the time I wasn't really coherent: it really messed with my brain. I couldn't focus on people for long periods of time. They would have half an hour of good conversation with me and then I would just close my eyes. I could listen, but couldn't really figure out what was going on, couldn't figure out if I was awake or asleep, if I was dreaming or if it was actually happening, it was just confusing.

"I've got a younger sister – she kind of deals with things a bit better than the rest of us, I think. But for me, she really helped me – always tried to make me laugh. One time she came into the hospital dressed as Justin Bieber, and

I was with a couple of other younger people in the room and they all burst out laughing. She was really good like that. But then, the whole family really bonded, I think. If there's one positive to come out of it: we're a really closer-knit family now."

She remembers being surprised by the level of pain she encountered after her hip replacement and the lengthy duration of rehabilitation: first on crutches and then a walking stick.

"All I wanted was independence; I couldn't wait to move out of home so I could just get away and do my own thing. And I was so dependent on people now: I couldn't get out of bed by myself, I had to get someone to pick up my leg and if I wanted to get up I had to ring the bell and call out in the middle of



the night [for someone] to come get me.”

At 18, after over a year of treatment and recovery, Alexis longed to begin the life she had planned – to be able to start university, work and go out with her friends.

“I still wasn’t quite mobile and I remember being at the cinema and these girls pointed and laughed at me and it was just horrible, because I really tried to hide my illness a lot of the time; most people couldn’t tell and if someone kind of picked up on it, I just got really defensive. I didn’t want people to know I was different; I just wanted to be normal.”

Slowly Alexis became more comfortable and confident, starting a nursing degree and briefly moving out of home.

The dilemma of being a young person in hospital peppers our conversation. Alexis remembers sharing rooms with much older people.

“You can hear other people’s stories and they don’t always have happy endings and there’s just a thin curtain – and you’re trying to block your ears, like you want to give them their privacy, but you can’t.

“They [could] try to put all the young people in the one room together, but they all come in on different days and you can’t kick someone out of their bed just so two young people can hang out together: that’s not fair on the [older] person. If there was a 16 to 30 year old ward you’d feel a little bit less isolated.”

She reflects on the manner in which information is imparted to young patients.

“I think they [the doctors] are more careful about what they say, ‘cause

“There were all of these emotions that I just wasn’t used to; I didn’t know how to deal with them”

I’m not sure everyone wants to hear a survival percentage.

“It was just kind of: ‘We’re going to do this and this and this and you’re going to live a long healthy life and you’re going to be fine’. I think in a way it’s kind of good because I actually never considered that I might die from it, I just felt: ‘Well, I just have to do this and then I’ll be fine’.”

Alexis refers often to the assistance and support she received from ONTrac at Peter Mac, the Victorian Adolescent and Young Adult Cancer Service, to deal

with the issues and emotional setbacks related to her treatment.

“But then a couple of rounds into it, I kind of got used to the routine and it just dawned on me and I just completely fell apart, ‘cause then I had lots of time to think about it. The psychologist came from ONTrac and also the educational liaison officer; she helped me with getting extensions and getting my exams to be sat at home instead of at the uni, things like that ... she organised me studying online and she was my go-to person for that. They gave me really great support.”

Working with a psychologist taught Alexis strategies to cope with her situation. “There were all of these



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emotions that I just wasn't used to; I didn't know how to deal with them. There was a bit of meditation and kind of taking a step back and looking at the emotion and seeing that 'that's a cancer emotion, that's where that's coming from' and just understanding it and then you can move on. We kind of called it a 'new kind of normal'. I had to kind of learn to just accept it, because even sometimes now I get a little bit of 'Oh, I had cancer' – like it still kind of shocks me, you know, when I think about it."

"Sometimes I think of it as my little secret: I don't usually tell many new people, because I don't want people to think of me differently or treat me special because they think you've been through such a tough time you should have life easy now or something. I try to think of myself as a normal person who just happened to have cancer, kind of a little attachment of me; I guess it's my personal baggage."

Three years after treatment, Alexis leads a busy life, watched over by parents less

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concerned now about her immediate survival. "Their worries have turned from, 'Oh my God, she might have to go back to hospital', to more normal, 'Oh, she's driving when she's tired' – normal parent sort of things."

Alexis offers advice to other young patients. "Start talking to someone now: [a] psychologist, social worker, someone. These should be tools you are armed with before treatment. You may not feel that you need it yet but you will".

"Don't put any expectations on yourself; don't feel guilt for bursting out into tears at inappropriate times or ... that you can't go to work and you may have to go on Centrelink, if you can get it.

"Focus on the good people that are there to support you."

Alexis has swapped nursing for a double degree in public health promotion and commerce. She intends to volunteer for the Cancer Council's SunSmart campaign over the summer, explaining that she has always been interested in health.

"I always wanted to help, so if I can give this cancer experience any meaning, at least I can make it less difficult for other people. It wouldn't be so pointless, I guess."

For information and resources regarding cancer survivorship see:

- petermac.org/cancersurvivorship
- petermac.org/cancer-information-resources
- www1.petermac.org/onTrac



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A Richard Pratt Legacy



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