

You survived childhood cancer, but who cares now?



Sheila Wayman

The aftermath of survival includes medical, psycho-social, fertility and financial issues

When Alan Gorman started having pain in his feet at the age of 17 during his first months at college, a doctor put it down to an unbalanced diet and not enough exercise, as he was living away from home for the first time.

Recommended vitamin supplements didn't sort the problem, nor did a further consultation with another doctor. And one Friday when he was home in Swords, two weeks before Christmas 2008, his mother had "got sick of me hobbling along", he says, and brought him to a Swift VHI clinic.

The doctor started asking him about other symptoms – "night sweats and other things I hadn't thought to put together". He then told Alan he needed to go straight to Beaumont Hospital. The nurse with him pointed out it was a Friday night, and surely it could wait until Monday.

"He gave her a kind of death glare and said, 'No, you're going to Beaumont Hospital tonight,'" and wrote out a long referral letter.

From there things moved very quickly to a diagnosis of Hodgkin lymphoma – a cancer of the lymphatic system, which can start in any part of the body. It was explained to him that his white blood cells were overproducing and attacking everything in his body.

Chemotherapy

Alan had to start chemotherapy treatment straight away and was advised to withdraw from college because he would be very prone to infections. Once the chemotherapy was over, Alan had already re-enrolled for his computer science course at Dundalk Institute of Technology for September 2009, when a scan showed he had relapsed and needed to go back for more treatment, including radiation.

"Again I had to withdraw from college and at this stage I was going mad," he re-

calls. The radiation didn't work either and he had to have stem cells transplanted in September 2009 at St James's. Some of his own stem cells were harvested for reintroduction after high-dose chemotherapy.

"That's when they thought it would all start working out, but it didn't." He had to go through a similar process again but this time using unrelated donor stem cells.

Alan was also given the high-tech drug Brentuximab on compassionate grounds, because of his age, even though it had not been licensed for use in Ireland at that stage.

After he had that drug treatment and a last top-up of donor stem cells, he reckons he was about 85 per cent recovered. "I am still trying to get back where I was but I will never be 100 per cent."

Vision loss in his right eye, a hip replacement and dental issues are just some of the legacy of the toxic treatment that was needed to keep him alive.

Follow-up care

For those who have survived cancer in childhood or adolescence, it's what happens next that is an untold story. Alan, now aged 28, can't fault the health system for the acute treatment he received, but the lack of co-ordinated follow-up care has been an issue in the seven years since.

Now a national assessment of cancer survivors' needs, the full results of which are due to be published shortly, has looked at the post-treatment experience of young patients and their parents, and identified gaps in services.

The research will inform the implementation of recommendations of the National Cancer Strategy 2017-2026. One recent significant step in this regard, reports Louise Mullen of the National Cancer Control Programme, was the recruitment of a national clinical lead for children, adolescent and young adult cancer.

About 200 children and young adolescents (0-16 years of age) are diagnosed with cancer in Ireland each year and all are referred to Our Lady's Children's Hospital Crumlin (OLCHC) in Dublin. With a survival rate of more than 80 per cent, there's increasing need for appropriate support over a long life-span, for issues that can range from the medical and psycho-social to fertility and financial.

"We're looking at the 'challenges of success', says Patricia McColgan, who co-founded CanCare4Living five years ago to advocate for young survivors. Her son, Rory McGrath, was diagnosed with cancer at age 14, and she has been campaigning tirelessly for appropriate long-term care, which would allow people like him "to go off and live their lives".



Dr Michael Capra, a paediatric oncologist at Our Lady's Hospital, stresses the importance of setting up a follow-up service that accurately reflects the patient's intensity of treatment. Not all will have "medical baggage" after their illness.

A survivorship programme "should not prolong the label of a medical need for patients who want and are able to become independent", he says. However, those who are likely to require ongoing, hospital-based care due to side effects can be predicted on the basis of the treatment they received.

For a number of years, the OLCHC has been generating a medical summary of treatment, or "patient passport", for young-

sters leaving its care. But now the hospital is working towards producing electronic versions, which the patients would be able to own and access.

The lack of any such co-ordinated medical record for those aged over 16 who are treated in adult services is one of the concerns highlighted in the survivorship needs research. Dr Peter Barrett, a specialist registrar in public health who worked with Mullen on the study, looked closely at the childhood/adolescent group.

"The more we looked into it, the more we realised this is a very distinct group with very distinct needs." They are experiencing medical and psycho-social effects that had not been documented in Ireland before.

Lack of communication

Young cancer survivors and their families say they need information about late effects to empower themselves. They want a summary record detailing diagnoses, treatment and risk profile for the future.

The lack of communication and co-ordination in follow-up care is another big concern.

"They could have received great treatment in a children's hospital but subsequent adult care could be split over multiple different hospitals," Barrett explains. As a result, there tends to be gaps in communication between the individuals they are attending.

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The report is recommending a single point of contact that could oversee survivors' needs and help them navigate the system. Much greater psycho-social support is also required. People who may have "ploughed through" treatment as a child or adolescent, Barrett says, talked about "delayed trauma, when they eventually processed what had happened. In some cases, this triggered a mental health crisis."

Not everyone would want counselling, he says, but they want the offer to be there. "At the moment they are mainly getting it by paying privately or going through a charity and the public supports are inadequate."

Losing a slice of childhood or adolescence to cancer also brings social challenges. The extent of educational supports, for instance, often just depends on the individual school or college the family is dealing with.

There is also the financial burden – necessitating remortgaging of the family home in one case – to cover the monetary fall-out from the illness. This can include loss of earnings, treatment fees and hidden costs, such as care for ongoing dental issues that many have to pay for privately.

Financial protection

The survivorship report is recommending more streamlined access to educational support and that ways of offering financial pro-



■ Above: Alan Gorman (28) was diagnosed with Hodgkin lymphoma at the age of 17: "I am still trying to get back where I was but I will never be 100 per cent." Left: Sarah O'Neill, from Drogheda, was still in school when she got her cancer diagnosis: "If they had said to me your life will never be the same again, I would feel better. I think I struggled for a long time."

PHOTOGRAPH: NICK BRADSHAW & DARA MAC DONAILL

tection be looked at, such as extending the eligibility of the medical card. Currently, entitlement to a medical card expires five years after the end of treatment. Depending on the type of cancer, some survivors get a long-term illness card while others don't.

Alan is glad that he, at least, is eligible for

free treatment at the Dublin Dental Hospital where he had to have three teeth extracted last year and faces a root-canal-type procedure in the coming months.

For a complete treatment summary record, he would have to retrieve details not only from St James's, which is now his primary care centre, but also the Mater, Beaumont and the Dublin Dental Hospital, and compile it himself. Although his family did keep their own unofficial record.

The need for communication between different medical services was highlighted for Alan when he went for a hip replacement in 2008. The anaesthetist, who hadn't been informed that his patient had had Hodgkin's lymphoma, refused to proceed due to what he saw on an X-ray. The surgery was rescheduled for a couple of weeks later after this was explained.

Overall, I am doing well, Alan reports. But he can't help feeling his early 20s were more or less written off.

"I had plans where I wanted to be by the time I got to this age. That all had to be derailed." He never did go back to Dundalk IT. Instead he studied multi-media and communications at Coláiste Dhúlaigh in north Dublin before progressing to a BA in Film and

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TV production there. He has since completed a diploma in further education and is looking for a teaching job.

"When I first finished my treatment, I was very lethargic. I had to force myself to move and go and meet friends, or go out to college."

On the day we talk, he had earlier spent an hour working out in the gym. "Three years ago, I would have been done after 10 or 15 minutes. It has been slow and it has been gradual but it has been improving."

He has ongoing issues with his feet, where lymph nodes pushing down on the muscles caused the sensation of "walking on a pebbly beach".

"My feet are still not 100 per cent. I have foot drop. If I'm not in socks or shoes, there is a very good chance I am going to trip over my own toes."

He knows there are non-health challenges ahead too. "I have been told I am going to find it very hard to get life insurance because of the cancer diagnosis and everything else. Unfortunately, then without life insurance, you can't get a mortgage, so I am dreading that aspect."

For some young adults like Alan, life after cancer is never straightforward.

Masters or frozen eggs

"Do I do my Masters or freeze my eggs?" Sarah O'Neill's dilemma over such a financial choice is not one many other 21-year-old students face.

But as a survivor of teenage cancer, she knows her fertility is precarious. There was no time to address the issue between diagnosis and start of treatment back in 2014, not that she gave it much heed at the time, when she was about to enter her final year of school.

She remembers her mother asking the doctor delivering the diagnosis, "Well, what about children?" and I was like "I don't want children!" She had injections to "put my ovaries to sleep" to help protect them but it was a relatively new drug and its long-term effectiveness is still unknown.

Banking of sperm before treatment is relatively straightforward but there is concern that this option is not automatically raised for all post-pubescent males. Any procedure to safeguard fertility is free to cancer patients before treatment but, down the

line, they have to pay the full cost from private service providers.

Fertility is just one issue preying on the mind of Sarah who is frank that 2018 was "my worst year mentally". At the time of her treatment, everything happened so fast she just had to go with it.

She remembers at diagnosis being told "just give us a year of your life and then it will go back to normal". Whereas, "If they had said to me your life will never be the same again, I would feel better. I think I struggled for a long time with why am I feeling like this." It was only when she met other people who had gone through something similar, she realised others do feel like this.

"The idea that you can put what happened to you in a box and stash it away in a corner isn't realistic."

Sarah will be talking about her experiences at a CanCare4Living "roadshow" in her native town of Drogheda, Co Meath this Thursday, January 24th.

Chestpains

She started having chest pains in February 2014, but she went to the gym regularly and it was put down to a pulled muscle. The pain would come and go "so I never really got on top of it".

But one night in June she was lying in bed at home and "I couldn't breathe it was so bad". She texted her mother, Sharon, to say she wanted to go to the hospital in the morning but "she came straight into me and said 'we're going now'".

From an X-ray, hospital staff thought initially it looked like pneumonia. But it turned out to be a tumour blocking her lung.

"It was quite big – 15 x 8 x 5 centimetres", she says matter of factly. "It covered my whole left lung."

The diagnosis was made at the Mater in Dublin on a Monday and she started chemo on the Wednesday. "They said I wouldn't have made it to the weekend."

After six months of treatment, she needed surgery to remove residual tissue and that was followed by radiation as a precaution. However, in between the two, she sat her Leaving Certificate in June 2015, even though she had been in school for only six days of sixth year. Although encouraged to take a year out, she had wanted to finish with the girls she had started with.

Keen to study nursing after her hospital experience, she decided she could get enough points to do a PLC course.

Sarah has been in remission since September 2015, when she started a pre-nursing course. "I liked the course but I didn't like the placement so I decided I didn't want to be a nurse and now I am studying Health and Society at DCU."

She still attends six-monthly check-ups but is frustrated that she sees a different registrar every time and has to explain herself on every visit.

"It's like I am going into them so that they can tick a box." She doesn't feel it's really about trying to improve her situation. What's more, she has to sit in a waiting room for two hours for that five-minute session.

She still has sporadic pains in her chest and was going to start physiotherapy that would include massages. However, the physio said she would have to get clearance from the hospital to do this. That was back in April.

"I rang five or six times, and I haven't got through to anybody because they are so busy." She understands that but, if there was one point of contact to streamline matters such as this, it would be so much easier, she points out.

Her experience in this regard doesn't augur well for obtaining the treatment summary she is hoping to get in the future.

"I think everybody should have it," she adds. "I want to go away when I finish college and travel."

Cancer survivors, families, friends and supporters, advocacy groups, healthcare professionals and researchers are invited to attend the CanCare4Living Roadshow at the Westcourt Hotel, Drogheda, Co Meath on January 24th, starting at 7pm. For more information, see cancare4living.ie