



Airing Pain

Edition 141: Living with Childhood and Young Adult Cancer

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Begin transcript

Paul Evans

This is ***Airing Pain***, a programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain, our family and supporters and the health professionals who care for us. I'm Paul Evans and this is the second edition of ***Airing Pain*** focusing on issues faced by children and young adults.

Professor Emeritus Sam Ahmedzai

I can't imagine the teenager that has a life which just runs smoothly. Everything changes, their relationships with their parents, with their school, with their mates and their, you know, interests in life, they're constantly changing. Along comes cancer. That's the big game-changer. Nobody expects that to happen to a young child or a teenager, and that takes a lot to acclimatise to and to live with.

Evans

With over three decades of experience Emeritus Professor Sam Ahmedzai is internationally recognised for his work within the field of cancer. Indeed, he was a pioneer in setting up the speciality of palliative medicine. I spoke to him at the 2022 annual scientific meeting of the British Pain Society.

Ahmedzai

When I was initially training in oncology I was interested in, and my research was measuring, quality of life in cancer patients. So, I was asking lots of questions about symptoms and how it impacted on people. Pain kept coming up as one of the most dreaded symptoms and having a huge impact on peoples' lives. Back in the 80s we were not actually very clever at how to manage it. We were still just getting to use drugs and interventions. We're much more sophisticated and more successful now but it was the big thing that had a big impact and I'm kind of proud to say that in the last 30 years pain has actually fallen down as the



number one concern. In cancer, across the board, fatigue is the big issue. Pain is still there but, because we recognise it, we jump in there and all of palliative care services, all of oncology, is very good at picking up and managing pain. It's still a problem but it's not the number one problem any more.

One of the most challenging, but also the most rewarding parts of my work in the last ten years before I retired, I was the supportive care lead for The Teenage Cancer Unit in Sheffield. I guess it helps that I've brought up some teenagers myself so I know how teenagers think and act and how you don't tell teenagers what to do. You lead them - gently. But, when we talk about young adults - teenagers and young adults – 'TYA' - when I was starting to do this it was sort of from 16 up to 21 then 25. We're now talking up to 30 or even 40 years after cancer treatment as a child or teenager because one of the things we've discovered is that the late effects of some of the treatments we use very successfully to eradicate the cancer – surgery, radiation, chemotherapy, high dose treatments like bone marrow transplants – they can have effects sometimes 10/20 years later.

Evans

Physical effects or mental effects?

Ahmedzai

The main way that the late effects come out is in terms of hormonal changes. People who've had cancer treatment early on in their formative years/adolescent years, children – adolescents - have, sometimes, disturbances of their endocrine system and may be affecting fertility, for instance, growth – those sorts of things – but they're more likely to develop diabetes and other long-term complications. Some of the late effects are very painful when we use, for instance, high dose steroids in managing people who are going through stem cell transplant as we do for many teenagers, children and teenage cancers. We find that 5 or 10 years later the joints are breaking down. The bone is dissolving. It's called avascular necrosis of bones and people find it hard to use their arms, their legs and we have to then sometimes use hip replacements and shoulder replacements. This is not something that we even knew about many years ago because people didn't live that long from teenage cancer but now we are using these intensive treatments which are extremely successful at eradicating cancer but they do take their toll on the body.



Evans

The effects of the cancer have gone – they're cured or in remission. And the patient is left with 'where do I go now? All my hopes and aspirations from before I had cancer, everything's been cut off but the cancer has gone but I'm still here ...'

Ahmedzai

Cancer is unlike many other illnesses, even serious illnesses – it's a real game changer. A person cannot live the life they did during and after having cancer. Fortunately we're getting much, much better at managing cancer, minimising it, eradicating it – sometimes with very long-term treatments. You know, immunotherapy can last for years but keeps the cancer at bay. What we want people to do is to try and live with the cancer. Not that it's always there every day. They don't wake up every day and say 'well, how I am going to manage cancer today?' You know how they approach their original work? Did they go back to work? Did they change their work? I was dealing a lot with teenagers who had cancer. And there the issue is when and how do they take up their studies again and go back to college or university or apprenticeships so people need help in navigating what many of us take for granted in life. We start off and we go through. Cancer comes up as a big barrier and you've got to get around that barrier or over that barrier and the landscape is different.

Evans

That's Professor Emeritus Sam Ahmedzai.

Well, as you'd expect, a child or a young teenager will be treated within a paediatric service. But, at the age of 18, they legally become an adult. How's that transition managed within cancer care?

Professor Diana Greenfield is a senior consultant nurse at Sheffield Teaching Hospital's NHS Trust, where she is also the multi-discipline team lead for the Late Effects Service.

Professor Diana Greenfield

We see patients who had childhood cancer and also who've had cancer during adolescence and in their 20s and 30s. We don't see them during treatment. We're referred to them from a number of different sources following their cancer treatment. And we look after them in



their medium to late recovery. Also, we do monitoring and surveillance for the long-term consequences of cancer and its treatment.

So that's my clinical service and, as a consultant nurse, I have, what we call, 'Pillars of Practice'. So as a consultant nurse we spend 50% or more time as clinical experts and leading clinical services and expert practice, but we also do research. We either lead on research or participate and support research endeavours - but my clinical expertise is in childhood cancer survivors.

Evans

What sort of ages are we talking about there?

Greenfield

In terms of NHS services, the teenage young adult cancer services are organised around young people from when they become a teenager at 13 up to their 25th birthday. So anyone who's diagnosed with a cancer diagnosis can have access to the Specialist Commissioned Teenage Young Adult Services. But those are often organised in different ways in different places. In Sheffield that's organised with the Children's Hospital. They see the younger teens from 13 up to their 16th birthday. If they started the treatment at 16 they might carry on. The Adult Services will care for young people with a new diagnosis of cancer from the age of 16 - they're in within the Teenage Services until their 25th birthday. Now, for the Late Effects Services, we actually do differ from other places in that we don't stop seeing them at their 25th birthday because late effects, by their own nature, are late. And so our service actually doesn't have an upper limit. So, for example, yesterday in clinic I had a childhood cancer survivor who's 67.

Evans

I find that astounding. So, what issues has he had from being a teenager to 67? I'm thinking that that's 50 years, 55 years?

Greenfield

He may not have been in the services all that time but, generally, he has lived well. But may have some long-term effects of the previous cancer treatment - the patients who are most at

risk are those who've had high doses of radiotherapy. Now the fact that he survived that long, we actually don't even have the records of what he had. It's extraordinary actually, we do have a radiotherapy radiographer who works within our service and has been amazing at digging out the records going back to, sort of, late 60s/early 70s and, of course, technology has changed as well so it was much more 'belt and braces'. It's more sophisticated now. But we pull out the treatment details for those patients and that's really important for us to understand the types of treatment or the treatment that patients had at that stage because that gives an indication of the sorts of risks and problems.

So, for that particular patient, they've done incredibly well, but there are some risks for that patient - they had a particular problem with their neck - because they had radiotherapy to their neck and they have lost a lot of strength in the neck. There are some risks associated with that, in terms of, they had radiotherapy to their chest, so they have risks in terms of lungs, heart, skin and other muscle and soft tissue problems.

Evans

Coming down the age scale a little bit, a lot actually, for the teenagers and adolescents, what sort of issues are they coming up with to see you?

Greenfield

It really depends on the type of cancer the young person has had. And the kind of treatment they've had. So, the cancer they've had, the staging they've had, whether it was late presenting, how advanced the cancer was - will determine the intensity of treatment. The more intense the treatment is the more likely there are going to be side effects and long-term effects. But for young people often if they have come through very well and responded very well to the treatment the issues may be around adjustment to their diagnosis. So, we know that there are recovery issues, both emotionally and physically, and there's often a lag between the two, so there may be a lag between the physical and emotional recovery. So, I can't say specifically what type of problems patients are there for because there isn't a 'typical'. It really depends on the cancer, on the treatment, on the resilience of the patient, on their family, on their circumstances. So, we treat every patient as an individual and really try and address their issues.



What we find is that pre-arming them with information does help in terms of managing expectations. So conveying information can be useful. But it also needs to be done skilfully because you can overload with information and our patients may not be ready to listen or hear. So, we do have to take things on an individual basis. Individuals have different capacities for taking on information and want it in certain ways. So, it really is a very individual matter of both their individual risks and how you convey the information to them and their families.

Evans

Is this what you mean by person-centred holistic care?

Greenfield

That's exactly what it is. It's about considering not just their medical care and their medical needs, but also their psychological and emotional needs at a time of great change. So, for a young person *without* cancer, it can be a tumultuous time of change - of transition between child and adult – and that doesn't happen overnight. We know that doesn't happen. The young person's brain is immature until their mid-20s so that's why there are services until that stage. And there is great variability within that. So, we need to consider the personalised care which considers their own maturity, their own stage of development and consider their medical, physical, emotional and social needs as well. So, it's very much a personalised holistic service.

Evans

Because I'm just thinking the teenage years - my own teenage years a long time ago - my children's teenage years, and now my granddaughter's teenage years. They're a tough time without health conditions.

Greenfield

It certainly is and it's challenging for the whole family and I think this is where Adult Services need to learn a lot more from Paediatric Services where Paediatric Services are the experts in giving holistic and providing holistic patient-centred, but *family*-centred, care and I'm very much an advocate for family in its broader sense, you know, family can be described as a



house or a unit of care. It doesn't necessarily mean the traditional family and we need to consider that approach as much as we can and deliver that within Adult Services. And that's not always easy because we don't have the same resources or facilities or ratios that we have that are seen often in children's settings.

Evans

So, do you deal with people individually *and* as a group? Parents, supporters, Guardians?

Greenfield

So well, of course, you will see a huge variety of young people and their circumstances – so we may see patients and young people who are living independently at 17, and may have even started their own family, and then you might see in the same clinic a 17/18 year old who's still really very immature or just not ready to develop so much and are very dependent. But what we must recognise is, of course, when a young person becomes an adult. In the Adult Services our duty of care is for that individual so we do try and ensure that we have a sole consultation, or at least part of the consultation is a sole consultation, with that young person. And it's about negotiating with the family and ensuring they're on board with that. So, that they step out at the right time, that the young person is OK with that and doesn't feel too threatened.

So, it is about managing that delicately to ensure that our young people *are* centre stage and our duty of care is with them. And that's quite difficult sometimes for the parents to let go. So, for example, we had a parent yesterday who emailed us and wanted clinical information about their son, and no doubt they had their child's express wish for that, but the son was 32 so we actually have to make sure, that we have the consent of the individual. And it does depend on their capacity, of course, so we need to establish and record what capacity the young person has and we need to have the permissions to be able to communicate and we are certainly not able to give confidential information by e-mail. There are lots of tricky negotiations and circumstances that we take on an individual basis so that we can navigate those processes.

Evans



That's tough for parents or guardians or carers isn't it? They'll transition from being 17 to becoming 18 and *that*, actually, may be legally when your role as a parent has gone.

Greenfield

We do try and acknowledge that. So often we still see sort of 17/18/19 year old young people attending with their parents but, as they move into independence, they're coming alone and then we may not see them for a couple of years or so. And then we might start seeing them again and, this time, they've got long-term partners who start to attend. And it's interesting that when you discuss with the young people - there isn't a stereotype but, more often than not, the parents have the fresher memories. And, if a child was extremely young – hopefully they weren't – their memories aren't fresh and they weren't traumatised by what they had or experienced. But the adults and the parents still remember that. So, we do still try and remember the parents and what they went through although, of course, our Duty of Care is with the young person themselves.

Evans

Because we're talking about stages of life, we're talking about from teenage to young adults and you were talking about a patient who's in their 60s. There are many stages of life between early adulthood and 60s and more to come.

Greenfield

Absolutely. I actually discharged a patient last year who was in her early 70s who'd been coming - had actually high risk. So, there's no point in bringing people back if they don't have significant risks. And we had dealt with quite a few problems over the years but discharged her when she developed early Alzheimer's. She'd lived long enough to get a disease of old age and I felt that it was a success story in a way, sad for her, but a bit of a success story because, despite the fact that she *had* developed a number of late effects, she'd lived a good quality life for long enough to get a disease of old age. So that must be considered a success story.

Evans

That's Professor Diana Greenfield.



Of course, of those many stages of life, one group that are neither children, teenagers or seniors, for want of a better word, are the young adults in their 20s, 30s and 40s who've had cancer.

Shine Cancer supports a charity that provides support for people in that age range in person through their Shine networks in England, Wales and Scotland and online. Ceinwen Giles is Co-CEO.

Ceinwen Giles

People come to us at a huge range of times in their experience so we might have people join us while they're in treatment – even before they've started if they're just newly diagnosed. But we do increasingly have people who are living with cancer for longer periods of time and that might be because they have what's called a 'chronic' cancer. So, there are increasingly types of blood cancers, for example, where there are treatments and you, you can take the treatment and you would live for a very long time. And we also have people who are living with an incurable diagnosis but they might have time – and that could be anything from a few months to a few years. So, we support people across that range.

Evans

Tell me something about your cancer journey.

Giles

I was diagnosed with Stage 4 Non-Hodgkin Lymphoma 13 years ago and I developed it while I was pregnant, ended up getting very ill at the end of my pregnancy so didn't know that I had it. Had my daughter six weeks early and the doctors thought that I had some pregnancy complications and that was what was wrong with me. But I was really ill and I was getting iller. So spent weeks in the hospital while they ran kind of every test under the sun, and they discovered that I had Non-Hodgkin Lymphoma. So, it was very advanced by the time they found it – I was in a tremendous amount of pain, I was very unwell, I couldn't eat, I couldn't really walk very far. I was told that the best thing that I could do was join a clinical trial that was going on in the hospital but it meant I had to stay in the hospital for six months. So, I did that and stayed in the hospital for six months, receiving treatment. At the time I didn't know anybody who'd had cancer. No-one in my family had had cancer. I didn't



know anything about cancer or cancer treatment, so it was, it was really new and I certainly didn't know anyone who'd had cancer and a baby. I didn't know those two things could go hand in hand. So, it was a real shock to the system.

Evans

What sort of emotional support did you get – or from meeting other people in your situation?

Giles

Well, I didn't meet anyone like me for 18 months, probably a year. So, when I came out I think I was just very focused on spending time with my daughter and trying to recover some of my strength. But everywhere I looked cancer patients were much older. The cancer I had is much more common in, kind of, men who were over 70. You know they were all lovely - everyone I got in touch with via different charities – it was lovely but I didn't really have anything in common with them because, you know, they were retired, they had their houses, their children were grown and all that kind of stuff. And, so, it was really only when I met my co-founder from Shine, Emma – and that was through another charity who I emailed saying 'do you have anything for younger people?' - and they said we don't but we know this woman. So, I got in touch with her and that's really how we started Shine. And it was because she'd had a very similar situation and hadn't met anyone her own age for years and when you *do* meet someone your own age in that situation it's really powerful. And it just made a huge difference to me.

Evans

What are the sort of issues that people in their 20s and 30s and 40s face?

Giles

Some of them will be similar to older/younger people so, you know, there will be things around mental and emotional health which are common, but I think, for a lot of people in the age group we support, you know, they struggle with uncertainty and what their diagnosis means for the future that they had planned. So, if you're at the start of your career, you know, you might have been thinking 'well I'm going to work really hard for the next five years



and get to this next point' and then, all of a sudden, you're in a situation where you can't work that hard anymore because you don't feel well – that's really difficult.

So work is a big issue. Mental health is a big issue. We also often talk in our groups about fertility. So, cancer and cancer treatment can both have an impact on your fertility and a lot of the advice that's given is not of very good quality or it's not given when you need it. It can be quite hard to get the right referrals so people can really struggle with that. You know, they were planning to have a family and they can't anymore or it's not going to be as straightforward as they would have liked.

And then there's a lot of issues, I think, around things like relationships and dating. So, you know. I think a lot of cancer support is predicated on the idea that people are older and they're retired but actually, if you're 30 and you don't have a long-term partner and you're looking well, cancer can be quite a big thing to bring into that, you know. At what point do you tell someone you're dating that you've had cancer, you might not be able to have children or you're in treatment, that kind of thing. So, there are quite a lot of specific issues, I think, that people in this age group really cope with.

We actually have a project that we're working on at the moment which is looking at how we can better support people who are coming out of what are called Teenage and Young Adult Services and going in to Adult Services - so that kind of age group, around 24/25. There's quite a lot of help and support available if you are treated as a, they call it, TYA – Teenage and Young Adult, and then you kind of get thrust into Adult Services with none of that support and that can be quite destabilising as well.

We've been doing interviews at the moment because we want to design a program to help people and people tell us that they were just told that they're moving to Adult Services and that's it. But what that means is, you know, the relationships that they've built up with the clinical staff or psychologists or other social workers – it all changes - and those people who have helped them aren't there anymore. And I think Adult Services do really rely on people being more, well, more adult [laughs], you know, more able to manage everything and to look after things and that's quite difficult if you've come from a place where you have people helping to manage your care and then, all of a sudden, you're thrust into an Adult Service which, to be honest, as an *adult* is very difficult to manage and negotiate. We could do better as a health system in terms of how we take people who are leaving Teenage and



Young Adult Services and going into Adult Services and helping them navigate that, understanding what's expected of them, who they can go to for help, you know, who will be managing their care. I think that was probably tricky before the pandemic but it's even more difficult now just because the staff are so stretched and burned out.

Evans

That's Ceinwen Giles of the charity, Shine Cancer Support, and their website is shinecancersupport.org. That's shine cancer support, no gaps, shinecancersupport dot org.

Now, as in every edition of *Airing Pain*, I'd like to remind you of the small print - that whilst we in Pain Concern believe the information and opinions on *Airing Pain* are accurate and sound, based on the best judgments available, you should always consult your health professionals on any matter relating to your health and well-being. They're the only people who know you and your circumstances and therefore the appropriate action to take on your behalf.

Now, it's important for us at Pain Concern, to have your feedback on these podcasts so that we know that what we're doing is relevant and useful and to know what we're doing well and maybe not so well. So do please leave your comments or ratings on whichever platform you're listening to this on or the Pain Concern website which is painconcern.org.uk. That will help us develop and plan future editions of *Airing Pain* and there are links to all organisations mentioned in this edition of *Airing Pain* and much more at that website. Once again, painconcern.org.uk.

Now, earlier, we heard from Senior Consultant Nurse Professor Diana Greenfield. So, from experience, are there key messages, particularly for teenagers and young adults, going through their cancer journey.

Greenfield

From a young person's perspective it's about living their life, enjoying themselves. They didn't go through the cancer and cancer treatment *not* to have the opportunity to make the most of their future. Balancing that with keeping themselves as fit and healthy as possible, and not being too risky with their behaviours. So, the same health messages apply to young people as they do to others – so we really want them to avoid smoking, drinking to excess



and taking street drugs/recreational drugs. We want them to take lots of physical activity and exercise for cardiovascular health. So, the same health messages but also to be vigilant - if they are persistently unwell, for more than two to three weeks, they need to seek medical attention.

And we also have messages for any healthcare professional looking after them. So very few GPs, very few healthcare professionals, will have seen a child cancer survivor and a cancer history is potentially highly relevant. So, our messages to them are if a young person has got a history of cancer they need to be more vigilant and they need to have a lower threshold for investigation.

Those are the key messages really. More vigilance without being overwhelming and obsessive and also a lower threshold of investigation. But we want you to have a healthy, long life.

Evans

Professor Diana Greenfield.

So, the last words in this edition of *Airing Pain* to Ceinwen Giles of Shine Cancer Support.

Giles

You know that scene at the end of the Wizard of Oz where Dorothy, you know, she pulls back the curtain and the Wizard is not at all who she thought it was. I often think, like being diagnosed with cancer or any serious illness is a bit like that. Like life isn't what you thought it was. You were all walking around thinking 'we're in control and we've got plans' and when you get really seriously ill it's like the veil is pulled from your eyes and you realise oh you're not nearly as in control as you thought you were. And for your friends and family it can often be the same thing, particularly your partner, because you had plans with your partner and now, all of a sudden, those things are different. And so *they* see life differently as well too. So, it's a really seismic shift, I think, and we underestimate the impact that, you know, a life-threatening illness can have on people.

Evans



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Transcribed by Fiona Lunn

Contributors

- Emeritus Professor Sam Ahmedzai, NIHR National Specialty Lead for Cancer
- Professor Diana Greenfield, Senior Consultant Nurse at Sheffield Teaching Hospitals Trust
- Ceinwen Giles, Co-CEO, Shine Cancer Support

Additional Resources

- [Shine Cancer Support, home - Cancer support charity for young people - Shine \(shinecancersupport.org\)](https://shinecancersupport.org)
- [Shine Cancer Support Podcast: Not your Grandma's Cancer Show](#)
- [Families and Children Resource Page - Pain Concern](#)
- [Airing Pain 118: Pain Management in Young People - Pain Concern](#)
- [Airing Pain 106: Pain Education For Doctors, Patients And Parents - Pain Concern](#)

Contact:

- Pain Concern, Unit 1-3, 62-66 Newcraighall Road, Fort Kinnaird, Edinburgh, EH15 3HS
Telephone: 0300 102 0162
Email: info@painconcern.org.uk

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Newcraighall Road, Edinburgh EH15 3HS