

Airing Pain Programme 66: Not a burden

The challenges facing young people in caring roles and ways to support them.

Friends don't always understand, they don't get out much and they're faced with daunting responsibilities, but they wouldn't change a thing about their families. So say the young people Paul Evans meets at a support day for carers in south east Wales.

There are 178,000 young carers in England and Wales doing unpaid work for parents too ill to perform essential household tasks or even look after themselves. Kerris Olsen-Jones, who works to support these children and young people – some as young as five years old – says that they sometimes 'miss the opportunity to be children'. She and her colleagues help the young people to socialise and make the most of the opportunities available to them.

However, many young carers do not see themselves as carers, so may not get access to support. Ethan Mason, who cares for his mother who has fibromyalgia, describes how as an adolescent he had to deal with a house fire alone, while fire safety officer Julie Goodfield gives fire prevention tips for people with disabilities and their carers.

More information on support for young carers can be found at www.childreninwales.org.uk

*Visit our webpage for young adult carers to listen to more **Airing Pain** programmes on this topic and find out more about the help available across the UK:*

www.painconcern.org.uk/how-we-help/young-adults.

Paul Evans: Hello, I'm Paul Evans and *welcome* to **Airing Pain** the programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain and healthcare professionals.

Youngsters: I'm Amy Vernon, I'm Sophie Carroll, I'm Adrian Griffiths and I'm Tom Hall.

Evans: And where are we today, what we doing?

All: We're are at the Welsh International Climbing Centre,

Evans: It will all become clear in just a moment [laughs]. Now according to the last UK census – that was in 2011 – there were just under 170,000 young unpaid carers – that's five to seventeen year olds – in England and Wales. Over all, Wales had the highest proportion, with more than 11,500 young carers. Two years after that census, the Welsh Government

set out its carers strategy for Wales, in which five priority areas were identified. Health and Social Care, Identification, Information and Consultation, carers and employment, young carers and young adult carers and support and a life outside the caring role.

And it's those last two priorities that bring me here to the County Borough of Rhondda Cynon Taf – you'll hear it called 'RCT' for short – in what was the heart of the mining and iron industries, in Wales's south eastern corner.

Amy, Sophie, Adrian and Tom are amongst the thirty or so young and young adult carers on a three day residential activity, social and education break. So what's in store for them?

Adrian and Sophie: What we're doing is sexual health, fire safety, alcohol and drugs and all I know is on Thursday we're doing caving or rock climbing.

Sophie: I'm doing Zumba.

Evans: But you're all young adult carers.

Adrian: I'm a young carer. I'm only 17, but I'm 18 in August.

Sophie: Aw, bless!

Evans: So who do you care for?

Adrian: My mother.

Evans: Why does she need caring for?

Adrian: 'Cos she has pulmonary hypertension, which is basically clots on the lungs. She had an operation but her chest is that much open now, it's opening slowly cos she had an infection when she came home and they took the bars out without telling her and now her chest is basically like that [indicates width] and don't blame me I've never tried and I never want to, nor has she, but she says she can feel the gap and if you want to, you can poke down with your arm.

Evans: What does being a young carer for your mother mean to you?

Adrian: It means I have to do more caring than other people, basically. So whenever people say, 'Do you want to come out?' and I say, 'I've got to care for my Mum' – and I don't mind doing that – I'm not one of those people who say [groan] 'I hate caring for my mum.'

Sophie: Then again, you must mind.

Adrian: The only thing I don't like is when your friends say 'do you want to come out' and I say 'I'm caring for my mother' – they think it's just an excuse.

Sophie: Yeah, I've had that before.

Adrian: And the only faraway place I've ever gone without my mother is Thorpe Park and Drake Manor and that's basically one day.

Evans: So your mum is reliant on you?

Adrian: I do care for my mother a lot, say I am not there, my sisters will do it for me, 'cos they're here too. She does do some things herself, even though it kills her to do it. Like if my father is in work and I'm not here to help and neither are my sisters, she will get up and do the washing and do whatever she needs and we'll come home and she'll be there doubled over and breathing heavily. What upsets me is she will do all that and she wouldn't have asked anyone else to do it. That's why I love her so much.

Sophie, Amy Tom: Aw!

Kerris Olen-Jones: My name is Kerris Olsen-Jones and I work with young adult carers in RCT. So that's carers, who've got a parent, neighbour or relative who've got some sort of disability, and they have to be between the ages of 18 and 25.

Evans: So young adult carers start at 18.

Olsen-Jones: Yes, yes.

Evans: But there are people that are a lot younger than that – they're young carers.

Olsen-Jones: Yes, that's right and we have girls in our team who work specifically with young carers.

Evans: We're in the Borough of Rhondda Cynon Taf, which is the industrial South East of Wales, the most populated part of South Wales. Now, tell me about the young carer project you're involved with.

Olsen-Jones: The Young Carer Project basically involves us as a team, going out, taking in referrals and going out and doing assessments on the young people to establish their needs and the needs of the family, as we cater for the family unit. We then commission a project, that Action for Children run at the moment, and that gives each young carer an opportunity to go to a group and meet up with other young carers in similar situations and similar age groups on a weekly basis.

To be able to go to the project, they have to be five years old and then they go to the project until they're 17. Although we have experienced and done assessments on people who were younger than that and have some caring responsibility, although they can't access the project until they are five years old.

Evans: Five years is incredibly young, what issues do they face?

Olsen-Jones: It could be anything from putting the washing in, 'cos mum's not able to bend down to the washing machine or mum's not able to turn the dials on the microwave, so maybe doing that. We had some people who've helped mum up the stairs. There's loads of different situations we've come across [of carers] as young as five years old.

Evans: What's your name then?

Leon: My name's Leon.

Evans: How old are you?

Leon: I'm fourteen.

Evans: Who do you care for Leon?

Leon: My mother.

Evans: What's the matter with her?

Leon: She suffers with depression, she's got anxiety, so I have to go with her to places so she feels safe. I have to look after her and the house. I go places with her like shopping 'cos she can't go on her own and I help her clean the house and organise things.

Evans: Do you feel you're missing out on things because you're looking after Mum?

Leon: I don't go out much because I have to look after her but I've started going out places.

Evans: What does mum think about the way you look after her?

Leon: She finds me very helpful, it's a good job that I help her, if not she'd be even worse.

Evans: So what's it like coming away with other young carers, like we have today?

Leon: I think the Young Carers is a really good operation because you get to go out to other places. You get to be accompanied and you find new friends. This is my first time here and

I've found two or three new friends already. It's really good it is, it's a good way to get out of the house and they also do support, helping your parents and that.

[Background conversation]

DJ: My names DJ and we're here at something called the Summit Centre. It has a big climbing wall and there's loads of activities. What we're doing right now is the team building tasks and it's a lovely Welsh day, a bit overcast with a slight chance of drizzle and, yeah, we'll see how it goes.

[To audience] On your marks, get set, go!

Evans: They're all very shy and quiet at the moment.

DJ: Yes indeed. Probably the first problem that's around is the lack of communication between these teams, so we'll work on that and see what happens.

Adrian: I don't know what any of your mothers or whoever you care for is like but to me no-one can compare with my mother.

Sophie: No, same here or my brother, both of them.

Evans: So you look after your mother?

Sophie: And my brother. My father is not on the scene. I don't think I would change what I do now.

Adrian: Even though my mother is ill, the only thing I'd do to change things is obviously to make her better, I wouldn't swap her for the world.

Sophie: I wouldn't, see? I know my brother's got autism and my mother's got depression but I wouldn't even change their illnesses, otherwise I wouldn't have the memories I've got.

Evans: When you say you wouldn't change anything because you've got all these memories, what do you mean? I don't understand that.

Sophie: My brother has autism so he can go on *forever* talking about a specific thing, or something like that and he can do these random things and he does things to his radio up in his bedroom and when you come in he immediately shuts up and shrink down in his chair and stuff like that. And when he's on holiday he can do completely random things. He'll be sitting here one minute then he'll get up and start dancing.

It's memories like that, it's the same as my mum, even though she's got depression, she can have a day when she's on her arse all day and then one day she'll suddenly laugh at something on the TV and we'll laugh for an hour. It's stuff like that I wouldn't change, 'cos if they were 'normal', if you get what I mean, I wouldn't have those memories. I wouldn't have my brother in the school play spraying his teacher with silly string, you know so...

Adrian: [laughs] I know what you mean.

Tom: That's every kid's dream, isn't it?

Sophie: And his head teacher comes out and says, 'that's the end of the play' and he pulls a face... brilliant! If he didn't have autism, I'm not saying he wouldn't do that if he didn't, but I wouldn't have that memory.

Tom: Same as you, with all the memories, I wouldn't change her for the world.

Sophie: I wouldn't change it anyway 'cos we wouldn't get to come here, and this is actually quite fun and I've met a load of people that I wouldn't change either, like Deb, she's a worker by the way I used to have her in young carers. I don't regret meeting her for one minute.

Emma: She's awesome

Sophie: I tell everyone I meet, that I reckon she saved my life, 'cos when I first contacted her, I wasn't this person.

Evans: Who's Deb?

Sophie: She's a young carers worker. She's the first key worker I had and when I first came to Young Carers I wasn't the person I am now. I wouldn't talk to anyone. I'd literally sit and stare at the wall all day. Then I met Deb and she just sort of takes you and goes, 'right, you're gonna do this and I'll be there with you' and she brings you out of your shell and, like I say, she literally saved my life.

Adult activity leader: Before we get going on this one, what makes a good team?

Young carers: [shout] Communication, listening skills, understanding each other, all of us knowing what we're doing in the plan of things.

Adult activity leader: Definitely, that's a good one, with that in mind, the next challenge is to stand behind these... [Excited shouting] The ball is not allowed to stop moving, if it stops or goes backwards...

Sophie: But the other team *stopped*.

Adult activity leader: Yes, I know, they shouldn't have – gotta keep the ball rolling.

Sophie: Rolling, rolling, rolling...

Adult activity leader: Everybody happy?

Tom: I'm not unhappy... [laughs]

Adult activity leader: Well that's ok. I want you to have a little chat and work out how you're going to do it, have a little play and I'm going to time you to see if you can do it.

Sophie: I was suicidal when I first came here, I was going through a lot of stuff in school, being bullied because of my brother and mother and then one of the teachers in school recommended Young Carers. When I first went on it, Deb came to my house and I remember she was wearing this top, it had the queen from *Snow White*, the wicked queen, that's what she had that on the front of it. And that's what I remember and [laughs] she's about the same age as my mum and she's got the wicked queen on her top [laughs], then she came in.

The first time we went out I was really quiet. I didn't want to talk to anybody and she took me to the house, the big house, everybody knows that and I met this group of boys who, honest to God, were about the dullest people I've ever met. 'Cos we were just sitting here, we weren't talking, Deb got up in the middle of the room and said, 'This is Sophie, this is Jim, Bob, whatever and she got us together and then it seemed like we'd been there forever. I'm still friends with them now, I'm still friends. Everything with this has done a lot for me. I got into College through Young Carers. I got my best friend through here and my first boyfriend here [laughs] even thought that's a bit embarrassing [laughter].

Sophie: I've gained a lot from being on this course.

Adrian: This project does change you.

Sophie: It does change your life

Adrian: My personality was similar to yours – I'd be like, until someone talks to me, I wouldn't talk to anyone. And then Becky, Debs brought me out of my shell basically and then I met you lot and already in the first half an hour we've had a hell of a laugh.

Tom: I was exactly the same, before I started on the project, I didn't really go and talk to anyone – I just sort of stayed to myself. I've been on quite a few of these residential and other events and I've enjoyed it. It's really made me who I am today, basically.

Evans: Who do you care for?

Tom: I care for my mother.

Evans: What's she got?

Tom: She got MS (Multiple Sclerosis).

Evans: So what does that mean to you?

Tom: I'm not really sure where to start with it.

Evans: Does it isolate you?

Sophie: I think anyone who cares for someone – it isolates them, no matter what it is.

Tom: Yeah, I suppose it does in a way, yeah.

Evans: I know when I was caring for my father – admittedly, my father was in his eighties and I was in my fifties – the whole focus of your life changes, you can't actually think what's changed, but it has. Do you agree?

Young carers: Yeah.

Sophie: Yeah, I've been caring for them since I was six. I didn't realise, I thought it was what every kid does. I think that's why not many people come forward about it. You've got to have someone realise you are a young carer before you do. I thought every kid is doing this – every kid is looking after their mum when she cries. Every kid is helping their mother bathe their brother.

Evans: But how many kids have seen their parents cry, I certainly hadn't.

Adrian: It breaks my heart when my mother cries, that's part of the reason I care for her.

Sophie: Yeah, but you do it 'cos you want to. At the end of the day, you could always go to the doctors and say 'My mother is ill.'

Adrian and Sophie: And say 'Chuck her in hospital.'

Evans: I was going to use the word burden, but it's an incredible responsibility on somebody that young.

Olsen-Jones: Yeah, I think it's important to stress that lots of young people that we work with don't see it as a burden, they see it as part of their lives – they've always done it. They enjoy doing it. Often carers find they've got a strong relationship with the person that they care for because of the responsibility that they take on. It does have an impact on their life, on every aspect of their life but, *generally*, the young people are happy to do it and feel that they're doing something valuable.

Evans: The people I have spoken to today, what impresses me most is they seem incredibly mature, beyond their age.

Olsen-Jones: Yeah, they're really living the lives of adults as young people, because they have to, because that's the way they are living at home. They are incredibly responsible in many aspects of their life. But of course because of certain responsibilities they've got in their lives, they miss the opportunity to be children and sometimes you'll see the older carers are quite childlike in their ways.

Evans: We can hear it now. [Laughs] But that's another thing about this week away – they're allowed to be children.

Olsen-Jones: Yeah, yeah! We encourage them to mix, to socialise with people they haven't met before. We do team building events where we make sure they're split up from the people they know, so they develop those relationships with others. They don't usually get to socialise much as a group, they're quiet isolated. It's quite nice to give them the opportunity to just be themselves, forget about any stress or pressures at home and just enjoy their time here. [Young people laughing and playing in the background and discussing the game]

Adrian: My sisters were at school and for some reason – I don't know why, I don't remember – I was at home and my mother started crying and we shouted 'what's wrong?' And she said 'my chest feels like it's caving in'. We rang our nan and she and my sister came up and the ambulance came and she burst out crying, 'cos she don't like going into hospital. That's what got me upset and my older sister comforted me and then when I went down to the hospital in the afternoon and the doctor came in and he basically said it's touch and go [sobs]. Sorry.

Sophie: It's fine, don't worry.

Adrian: Well basically, she was in there for two weeks and the first week it was touch and go and every day I was crying, 'cos I love my mother too much and wouldn't want to lose her and I *dread* the day when that happens.

When I saw her in the bed and she had all this wire sticking in her arm and one in her chest – she had a thing going up her nose and down into her bronchioles and she also had a gas mask on. As soon as I walked in and saw that, I burst out and I had to walk out – I couldn't see my mother like that.

Now she's doing fine now she's back in the house and I'm very happy and when they finally rectify her chest and she obviously gets slowly better.

Evans: How do children come to your attention, do they have to apply or does it get spotted in school that they're under pressure?

Olsen-Jones: More and more it's getting spotted in school and that's because of the training that's being developed and implemented in schools at the moment due to legislation that's coming in in Wales called 'The Carers Measure'. So more and more we're getting referrals from schools and we get an odd number of different people – nurses, GP's, friends, anywhere really can make a referral to us. We just need to know their name and address and to know they're happy for us to pop along, we make contact and go along and do the assessment from there, but anyone can refer really.

Evans: So what do you assess? What's the process?

Olsen-Jones: So, there's a difference really between young adult carers – because they come under adult services – and young carers come under children's services. But the assessment process is basically looking at the family situation, the family's needs, looking at the carer's – the young person's – responsibility in the house – seeing if that's an acceptable amount of responsibility or not and then putting things in place, in order to support them in their role. And, obviously, if it's an unacceptable amount of caring that they're doing, then we've got to look closely into that, and we've got to get additional and different services in to support that.

Evans: Can I just ask you who you are, what your names are?

Emma: Emma.

Courtney: Courtney.

Evans: You're both young carers – tell me what that means, who do you care for?

Courtney: My mother, 'cos she's disabled, she can't do anything for herself, she depends on me and my father really.

Evans: In what way does she depend on you?

Courtney: In every way – getting dressed, having a bath, going to the toilet, everything.

Evans: How old are you, Courtney?

Courtney: Fourteen.

Evans: Do you get out to play with your friends?

Courtney: Sometimes I get out, like, on the weekends, when my father is here.

Evans: What does it mean for you?

Emma: Well, I care for my mother and my father – they're both classed as disabled, they're both dependent on me. I hardly ever go out, 'cos obviously, I've got responsibilities.

Evans: How important is it to get away with other young carers in a week like this?

Emma: It's alright like, 'cos it's a break but I do so worry about my mother, if she's coping.

Evans: How did you get involved with the Young Carers Project in the first place? I know you're young carers...

Emma: It was through my school because they were asking me to do E3 [A scheme providing schoolchildren with extra-curricular activities] and obviously I couldn't because my mother and father are disabled and they needed me there.

Evans: So it's the school who put you in touch with the Young Carers Project?

Emma: Yeah, yeah.

Evans: And you Courtney?

Courtney: It was my social worker.

Evans: Your social worker helped you. Are you glad she did?

Courtney: In a way, yeah, 'cos it's like a break away from it and things.

Julie Goodfield: Good afternoon all. My name is Julie Goodfield and I'm a home fire safety advisor for South Wales Fire and Rescue Service. My main job is to visit homes within the South Wales area, and generally talk about reducing the risk of fire in the home.

Evans: So what are you going to tell the young carers today?

Goodfield: It's little tips really to look out for. The first important one is to check they do have working smoke alarms in the property and then we talk about cooking methods and making sure things are switched off etc. and not left unattended. We also talk about what you would do in the event of a fire and [how] it's good practice to keep exit ways clear, especially having a night-time routine, making sure everything is switched off.

In most circumstances, I would advise ringing 999 and getting out of the property as soon as they possibly could anyway. But things like overloading electrical sockets. A lot of people don't seem to be aware that... a thirteen amp plug, anything more in there could be a bit of an overload. So it's general safety tips and advice about keeping safe in the home.

Evans: Is it more pertinent to young carers?

Goodfield: It's important for everyone just to take on board fire safety within the house and I think for young people it's good because they can perhaps advise older generations, especially with electrical sockets and that sometimes there is too much amperage being used, especially with things today like mobile phone chargers, Sky boxes, Xboxes and games, 'let's just chuck it into one socket and happy days'. But if you've got a lot of heat there, it's good advice again and safety and tips, right we'd better spread that out, rather than causing a fire.

Evans: I suppose one thing you have to get across is, if there is a fire, don't try and fight it.

Goodfield: Exactly, yeah, yeah, try to prevent the fire happening in the first place, so we discuss issues like cooking methods, candles, plug-in things like air fresheners that are left on, they can actually shatter as well. Get an escape plan in their minds. But in the event of fire, never tackle because it spread so quickly and so fast – we're talking under a minute. Unfortunately, especially at night-time when it's not visible, smoke can kill before the actual fire, so it's always good to test your smoke alarms regular. We do try and say test them once a week but if they just test them regular, just to put their minds at rest that they are working.

Goodfield: Have you all got smoke alarms at home? No?

Young carers: [In unison] Yes, yeah.

Goodfield: How often do you think you should test them?

Young carer 1: Every ten years.

Goodfield: *Every ten years !*

Young carer 1: Well that's what the fireman said to my nan.

Young carer 2: No, every week.

Goodfield: That's true in many aspects, but the ones we give out come with a ten year battery. It's still good to test them once a week, get into a little bit of a routine. Has anyone been involved in a fire?

Ethan: Me.

Goodfield: Are you happy to talk about it?

Evans: Tell me your name.

Ethan: Ethan Mason.

Evans: And you're a young carer?

Ethan: Yeah.

Evans: Who do you care for?

Ethan: I care for my mother, she was diagnosed with fibromyalgia and ME (myalgic encephalopathy, previously encephalitis), so she finds it quite hard to go day by day. I have to care for her and look after her and that.

Evans: So how does she rely on you?

Ethan: She finds it hard to get up in the morning. She finds it hard to do simple tasks. Then I have to help her with certain things. I have to help around the house, look after my siblings and stuff, yeah.

Evans: How old are your siblings?

Ethan: One's eleven and one's three.

Evans: We just had a talk from the Fire Safety Officer.

Ethan: Yeah.

Evans: You were saying you have had a fire in your house, tell me something about that.

Ethan: In the kitchen, there was an electrical fault and a fire started. I walked into the kitchen and obviously the flames were getting out of control, so I had to grab my sister and get her out of the house, My mum was sleeping at the time because she was unwell, so I had to get her out of the house and I had to ring the fire service to come and put the fire out. Because my mum was unwell, I had to get both my sisters out to try and protect them from the fire.

Evans: Some of the young adults that I have spoken to today have incredible love and loyalty towards their parents.

Olsen-Field: Oh yeah, definitely, It's like a mother's love really, but it's the child experiencing it for the parent. It's because they care for lots of their needs – they play that parent role to an extent and because of that they've got that loyalty there. There's love there. They've got what any parent would have. It's almost role reversal really, to an extent.

Evans: The education side, sexual health, cooking, fire safety, that all sounds very serious and it is serious but the impression I got, is that is that they're getting an awful lot out of just being together.

Olsen-Field: Oh yeah, the opportunity for them to get together, meet other people who are in similar situations to themselves and similar experiences, is really essential. Having the adult carers here also shows them what life might be like for them in a couple of years time when they hit that age and it really shows the young carers that they can still continue with their education, they can go to college and life doesn't stop because of their caring role.

Evans: My thanks to all those involved with the Rhondda Cynon Taf Young Carers Project in South Wales.

Don't forget that you can still download all the previous editions of ***Airing Pain*** or obtain CD copies direct from *Pain Concern*. If you'd to put a question to Pain Concern's panel of experts or just make a comment about these programmes, then please do so via our blog, message board, email, Twitter or even pen and paper.

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There's more information for and on young carers in Wales at childreninwales.org.uk that's one word childreninwales.org.uk.

Evans: One last question, how important is it for you all to get together at these residential courses?

Young carers: *Very important, very.*

Sophie: I'm gonna sound sappy right now but if I didn't have these lot to cheer me up, I *honestly* wouldn't be here.

Adrian: If it wasn't for this, you wouldn't know how other people felt and you'd feel like you are the only person doing this. In your case [Sophie] you'd think everyone else does this and it's normal. .

Sophie: Yeah, I don't think any of us would be the people we are, if we didn't come to things like this.

Adrian: If it wasn't for this, I wouldn't have the confidence to go to college.

Contributors

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