

Intimate not Intimidated:

It's Time to Talk about Sex and Disability

Junior, Shakira, Tom, Leah, Lucy, Charlotte and Amy:

JUNIOR

Just normal?

TOM

It plays a significant part of our relationship.

LEAH

Kind of like a tub of Pringles, once you pop you just can't stop!

LUCY

You just learn to be OK with yourself and be OK with your limitations as well which is really important when you've got a disability.

CHARLOTTE

It takes a lot of relationship building before you can say Helen could you put Tom in my sexy knickers please.

AMY

Sex and sexuality is a topic that I necessarily haven't explored myself as much as I probably should have.

TOM

I'm Tom. I'm married to Charlotte from Nottingham and I have Duchenne Muscular Dystrophy which is a serious and progressive muscle wasting disease.

CHARLOTTE

I'm Charlotte. I've been with Tom for two years and we got married this August. I'm from Nottingham and I've got a progressive neuromuscular disease.

LEAH

I'm Leah. I'm from Blackburn in Lancashire. I have SMA type 2, which is a neuromuscular condition meaning that my body becomes extremely weak and I struggle to do everyday tasks.

CHLOE

Hi, I'm Chloe and I am Leah's sister/PA.

LEAH

Sorry I'm...

CHLOE

Get your drama skills back.

CHARLOTTE

Your sex life.

TOM

Yeah so there's quite a few different aspects to our sex life that I can bring to your attention. One of the main things we use to help us have sex is the hoist. Basically, all it involves is me or Charlotte getting into the sling and getting hoisted over the top of each other.

CHARLOTTE

Our hoist at home only goes, has buttons that go up and down but the one on our honeymoon, do you remember, had like buttons that go left and right as well.

TOM

Yeah.

CHARLOTTE

And it was kind of like a scene from Wallace and Gromit, I was just kind of in the sling going backwards and forwards and up and down and like I just couldn't find the right buttons and just legs kind of like going everywhere and yeah, it was quite a scene.

LEAH

Does that mean mine or yours?

CHLOE

Yours! I don't know both of us.

LEAH

If I read it it'd been yours.

CHLOE

Yeah. Your sex life.

LEAH

It's a relatively short one. Obviously because it's only been just over two years since I lost my virginity, but I have undeniably had a lot of sex since then. Kind of like a tub of Pringles once you pop you just can't stop. Kind of, yeah, bit like that. To me sex is an important part of any relationship, whether that's a short fling or a long-term thing. It helps me to feel connected to whoever I'm with.

CHLOE

So, is there many difficulties with your sex life like with your disability?

LEAH

I think I've got more confident with it which makes guys more confident with it. So, like at first I was like really shy about like a lot of my scars and the hoisting. But that's got easier the more time's gone on and the more like, obviously the more you get to know someone it's a lot easier as well. But yeah, it's a challenge. Because obviously there's certain things that I'm never going to be able to do with my disability, there's certain positions you're never going to be able to do, certain things you're never going to be able to do. But it's about finding a way between both of you. And like whether you've known someone for one day or a year, you can still find a way between both of you. You know, it's like I say if they want it bad enough, they'll work harder for it. You know, it's one of them ain't it? It's not all coming for free, you've got to work for it.

TOM

I think what helps us [unclear 0:04:09] our PAs having a sense of humour.

CHARLOTTE

Especially when we call them in and like I'm still sitting on your face and you're suffocating and...

TOM

I think that accidental innuendos from PAs, make us laugh all the time and just having that general ability to laugh at those things [unclear 0:04:27] confidence in our ability to communicate with them about sex and intimacy.

CHARLOTTE

It's takes a lot of relationship building before you can say Helen, could you put Tom in my sexy knickers please. It's amazing when you have that relationship that you can do that and you can feel free to do that with your PAs because, you know, sex is a health and wellbeing need like as far as we're concerned.

JUNIOR

My name's Junior, from South London. And I have a tracheostomy.

SHAKIRA

Hi, I'm Shakira, I'm from South London and I'm Junior's sister.

JUNIOR

Everyone needs privacy at some point. There's no privacy when you have a challenge. I've experienced being in a care home and my girlfriend at the time wanted to stay over. And it turned into a big argument. Because the staff. They don't want to leave me and her to have our own personal time. Which I think is wrong. I am human, I do have rights. This was supposed to be my home. But it never felt like home. She had to sign an agreement form that she wanted to be online with me.

SHAKIRA

How did that make you feel?

JUNIOR

Angry, frustrated, I felt like my freedom was taken away. I didn't feel normal. I'm not going to miss out on life, just because of someone's negative mentality.

SHAKIRA

No.

LUCY

I think people just put us in a box. You know, we're asexual, not interested, not worthy, not valuable, not desirable. You're constantly fighting for rights and fighting for services and fighting for support. You start to internalise that you're not worthy. And then suddenly you're in a sex education class where everyone's the same, you might have disability specific bits that are more relevant for you and bits that aren't relevant for you, but actually if it's inclusive for everyone, why not.

I'm Lucy, I'm from Essex and I have a rare form of mitochondrial disease which has caused various complex medical needs and multiple organ failure, and I live at home with my mum, my sister and my assistance dog, Mollie.

AMY

Hi, my name's Amy. I'm from Taunton in Somerset. My disability causes severe muscular spasms, excessive fatigue and pain.

LUCY

So, did you get any sex education at school?

AMY

No, I don't really think many disabled people necessarily tend to get access to sex education. Tend to get just sort of pushed on the side a little bit. Seems like all my peers did, but I didn't. Did you?

LUCY

No nor did I. I didn't get any sex education. I think you got the basic period talk at school when you're in primary school but apart from that I was kind of kept out. And then I became too ill to go to school. The community services never really picked up kind of the sex education side of things. Everything I've kind of learned, I've learned on the internet, from my sister, from other people.

AMY

I was going to say so where do you learn about sex if you don't have that sex education?

LUCY

But also, you know, it's where do you learn about the disability specific sex education because the broad principles kind of, you can understand the medical stuff but how is it relevant to me? I don't find there's much information that relates to me as a person and my disability and how that affects, you know, what sex education I need.

AMY

When we're removed from having the sex education class with other peers, it excludes us.

LUCY

It's difficult because if you don't have that information, you can't know what is safe, know what is normal. You know, you have to emotionally prepare to be an adult, to be a sexual being. You have to go through that process all the time through from childhood into young adulthood and beyond. I think if you've never had that education, that information, that support, you're

not going to go out and know how to have a relationship. You're not going to have those social skills and that information behind you. And if you're not worthy of sex education, how are you ever going to be worthy of sex?

AMY

We need to be able to cater for the disabled, but it shouldn't have to have this big focus because it should just be natural and appreciated.

LUCY

Just should be part of diversity, we're all different and it just should be part of that natural spectrum. I think for me as well, when do I tell a partner that one day my life's going to prematurely end? You know, I wasn't supposed to make adulthood. I wasn't supposed to make 23. I'm now 25. I'm not going to live forever. We've had some really horrible conversations with my team about, you know, infections ending my life and complications. At what point do I reveal that to a partner because bringing people into my life, knowing I'm going to cause them pain is quite hard. And at first I very much felt that I was being selfish to want that. But now I think well better to have something short and sweet than have nothing at all. And surely someone that gets to know me and love me and can carry on my legacy after I've died and remember me is more important than that little bit of pain they'll go through. And if it's worth it, the pain will be worth it.

JUNIOR

Put yourselves in other people's shoes. How would you feel if you were deprived of what makes you human?

LUCY

If you're raised to think disabled people are other, they're not part of society, you're not going to assume they're part of every part of life.

CHARLOTTE

There's a general perception within the public that young people with complex disabilities, one, aren't interested in sex or that sex isn't relevant to them.

JUNIOR

Never let a disability stop you from being you.

TOM

Sex can be challenging in any relationship.

CHARLOTTE

This is our challenge, this is people that own it.

LEAH

It's OK to ask questions and sometimes you might get a funny look but you sort of have to be strong enough to say I'm doing it regardless.

LUCY

We're having to educate an entire or more than one generation about what we need, want and actually are deserving of having.

JUNIOR

I want to make a change. I want to talk for those who can't talk for themselves.

LEAH/CHLOE

#Let's talk about sex baby, let's talk about you and me, let's talk about all the good things and the bad things that may be, let's talk about sex# We're insane.

END OF RECORDING