



Becoming a Man

Life with Duchenne
muscular dystrophy

Craig McLean, Liam McLean and David Abbott



Hi. My name's Craig.
I'm 19 and live in
the West Midlands.
I took part in some
research about my
life with Duchenne.

Here's a bit of background about the research

- It focused on what it's like to live with Duchenne and become an adult.
- It was carried out by two researchers (David Abbott and John Carpenter) from Bristol University throughout 2007 and 2008.
- It involved 40 young men aged 15 to 33 who have Duchenne (and their families) from three regions of England – West Midlands, South West and North East.

The research covered things like:

- our experiences at school, college and university
- the support people receive
- what happens to services as you get older
- what people do with their social lives
- what it's like to live with Duchenne.

This leaflet tells you more about what the 40 young men said. We hope you find the information useful and that by learning from our experiences you are able to find the support you need.



My name's Liam, I'm
20 and also live in
the West Midlands.
Craig's my brother and
I also took part in the
research about living
with Duchenne. This
booklet is about letting
you know what people
like us have to say.

School, college and next steps

People had good and bad things to say about what school and college were like:

Good stuff

- some staff were helpful
- getting things on site, like hydrotherapy
- having friends and being included
- more independence.

Bad stuff

- access and getting around
- bullying
- sometimes being left out of things
- problems with transport.

Things can go pretty smoothly when you're at school or college. But what happens when it's time to leave school, or if you decide you don't want to carry on at college? Here's what some people said:

Steve wanted to leave school after his exams and get a job: *"I'd had enough of all the study and being a student. I wasn't enjoying it any more. I wanted to get a job."*

Jim wanted to leave college and do something else but wasn't sure what: *"I've got a year to do at college but I don't want to go back next year. I ain't got a clue what I want to do. I want more information."*

Nick wanted to go to university: *"I remember seeing information about university. I asked my teacher about it and we had various meetings. I pretty much decided I wanted to go there straight away."*

Big decisions can mean a lot of change which can be stressful. Lots of people said they'd like it if things were easier:

"It does seem to be that before you're 16 there is a plan – this happens, then that happens, and it's smooth. Then you hit a certain age and no one's thought about what happens next!"

For more information and support with planning for the future and advice on who to involve in the process, you can order a free copy of the Muscular Dystrophy Campaign's Guide to transition for 13 to 25 year olds with muscle disease.

The guide is divided into sections about funding, lifestyle, practical, medical and social issues. Examples of subjects covered in more detail are further education, housing, grants and benefits, diet, lifestyle and living independently.

Contact the Muscular Dystrophy Campaign's Information Service on 0800 652 6352 (freephone) or info@muscular-dystrophy.org to order your free copy.



A transition plan

If you have a statement of special educational needs at school you should have a meeting every year from the age of 14 until you leave school. This is called a transition plan and it helps you plan what you do next.

You can invite people to the meeting – your mum or dad, a teacher who you get on well with, your occupational therapist or social worker – anyone who might have good ideas about what you do next and be able to support you with making decisions. You are entitled to support with making choices as you get older and it is your school's job to organise this meeting.

If you're aged 13-19, you can find out more about how things should work by getting in touch with Connexions – www.connexions-direct.com

If you have left school or college you are still entitled to help and support. Contact the Muscular Dystrophy Campaign's Information Service on 0800 652 6352 (freephone) or email info@muscular-dystrophy.org

Having a social life

Everyone wants a good social life: friends, mates, places to go, things to do. It's no surprise that young men with Duchenne in this research wanted all these things too. Everyone wants to do things (which don't involve their parents) with their mates. It's an important part of getting older: *"I wouldn't want to go out on my own. If you don't have friends, what's the point? It's just boring if you can't do what you want because you've got to be with your parents."*

There were lots of things that people were into – music, computers, art, cars, TV, sport: *"There's a form of wheelchair football we can play. A lot of us love football so a couple of parents set up a team. It's amazing, I love it."*



Several young men said how much they wanted to have and drive a car. One 17-year-old had been through a driving assessment and got his provisional driving licence: *"It's been my lifelong ambition to drive. In February I got my provisional driving licence and it felt awesome! I want to let anyone else who is in my position know that if driving is your thing it can be possible, so don't be put off."*

Not everyone was happy with having enough friends or having a good enough social life, especially people who had finished at school or college. Jack was 22 and had finished college and lived at home: *"I don't really have anyone to go out with or anything."* Quite a lot of people were in Jack's position.

Some people lived away from home at residential college or university. They said that their social lives were pretty good and that they had quite a lot of independence: *"Everyone treats you as a normal person at uni. That's one of the main reasons I wanted to go – to get that contact with other people, to get out of the house, you know, like going out drinking."*

Four people had girlfriends and said this had made a big difference: *"It's much better. I've got a much more interesting life now. It's somebody to talk to."*

For more information about considerations for living independently, see chapter 16 of the Muscular Dystrophy Campaign's Guide to transition for 13-25 year olds with muscle disease. (See page 4 of this booklet for details on how to order your free copy)

Living with Duchenne

Living with Duchenne can be a hard thing to talk about. Most people said they didn't dwell on it. It was pretty much in the back of people's minds. Here's what some people said:

"In everyday life I don't think about it much."

"Sometimes you talk about it and sometimes you don't. I'm not bothered about talking about it though."

"I live with it everyday. I know what I need to know. I'm not really interested."

When people did want to talk about it, they usually talked to parents or friends but it wasn't always easy. Some people said it was hard to talk to their parents because they wanted to protect them; they didn't want their parents to get upset.

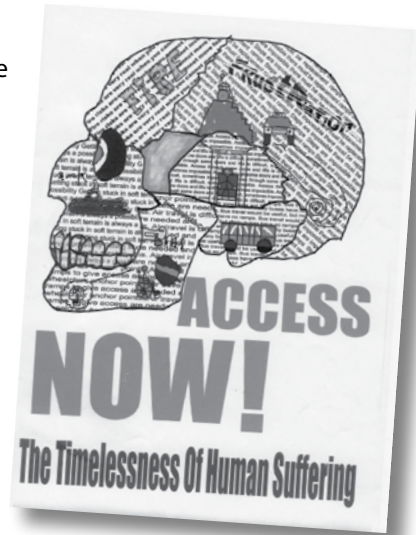


Jake said he talked to his mum if he had worries about his condition: *"I'd talk to my mum mainly. I don't feel that open with other people, not even some of my friends. There's not that many people to talk to. It's difficult..."*

Simon said he'd been part of a small group of other guys with Duchenne. He said it helped a lot: *"A while ago a couple of friends of mine had MD and we used to go to this meeting thing where we'd just go and talk about anything – like stuff we couldn't talk to mum and dad about. I mean we could talk about a really depressing subject but we'd have a laugh about it. And I'd come out of it feeling loads better."*

Want to talk about your feelings?

It might be that you can talk to friends and family about how you feel. Or you might find people online through networking websites, or blogs that are useful. But if you sometimes want to talk to someone else outside of your family and friends, you could talk to someone like a counsellor. Ask your GP if they can help sort this out. Or talk to any professional who you feel you get on with and ask them to help organise a counselling session.



Artwork(untitled) by James Kircher

There is a section in the Muscular Dystrophy Campaign's Guide to transition for 13-25 year olds with muscle disease called 'Social support and relationships'. You may find this helpful if you are looking for support with relationships and talking about feelings.

What happens to services you get as you get older?

You probably know that when you get to a certain age the doctors and other people you see might change. You might move from children's services to adults' services. Some people said this was a bit stressful and that they did not always know what to expect:

Charlie was concerned about what it would mean to go to adults' services: *"What is 'adults' services'? I don't have a clue. [I think] they deal with adults badly compared to children. I mean you just hear these stories that when you go into adults' services you don't get things as quickly."*

Lee had moved from seeing a consultant in children's services to one in adults' services: *"I've moved onto adult now. It took me a long time to want to swap really. But in the end I think it sort of automatically happened."*

Omar quite liked adults' services because he felt a bit more in charge of what was going on: *"I've been to quite a few hospital appointments without my parents there."*

Jack said that when he moved to adults' services he felt there were too many doctors to see but he made his own choice about what to do: *"I said I didn't want to see lots of different doctors all the time. The last thing I want is seeing a load of doctors who depress me with bad news! But I thought I'd better see someone, so I asked who would be the most use and I went for the respiratory consultant."*

A lot of people said that when they got older they didn't have things like physiotherapy or hydrotherapy. Iain said: *"Like physio, you get it till you're 16 and then, no idea what happens next. I don't get it anymore."*

For more information on how services change as you get older and what to do to access them, see chapter 25 'Social care' of the Muscular Dystrophy Campaign's Guide to transition for 13-25 year olds with muscle disease.

Having a job

Craig: We think this is a big topic. We've both been up for looking for work and having a job but it's been difficult.

Only one person in the research had ever had a job. There were lots of different views about work. Some people were not sure if they could get a job: *"I've heard that it's quite difficult for people who are disabled to get jobs."*

"When you think about jobs, you have to think about what's realistic and what's suitable for you."

Those people who did want to get a job said they might feel more independent, earn some money, and meet friends in the work place: *"If you've got a job you meet people and you become friends. Then you go out after work and maybe you meet their friends."*

Some people had been actively looking for work and found it very hard: *"I was looking into getting some work so I made an appointment to see the Disability Employment Advisor at the job centre, but she wasn't much good to be honest. She pretty much said straightaway that there wouldn't be any work that I'd be able to do. I was hoping for a bit more of a positive approach than that!"*

The one person who had been in a job had got the support he needed to do it – his transport to and from work was paid for, and he was assigned a job coach to help him get started and feel confident about the job: *"Yeah it was good. I enjoyed going to work and being with the people there."*

Liam: We think that people with Duchenne can get a job – if they get the right support. We know it's difficult but keep trying and think positive. Have you got a copy of the Muscular Dystrophy Campaign's Guide to transition for 13-25 year olds with muscle disease yet? Chapter 24 covers employment in lots of detail.

What helps?



I'm David and I did the interviews with the 40 young men who took part in the research project about transition. Quite a lot of problems came to light in the interviews. We also asked young people what had been good, or what would be helpful in the future. This is what they wanted:

Information about options post-school/college

People wanted not just general information, but specific information about real options: information about courses, work, daytime activities which people could get to and which happened in buildings they could access. Young people wanted information about things which were of interest to them and to be around people their own age: *"I'd like to go to like a place – like a youth club where they MC and stuff like that – I'd go and listen and watch."*

Being talked to like a real person

People didn't like going to appointments where people only talked to their parents. Young people liked it when they were treated as young adults and got involved in what was going on: *"Some places, like hospitals, can be great at patronising you. They're like, 'Is he alright?' and they talk to my parents. My mum says, 'Ask him yourself!'"*

Being supported by friendly professionals

Young men liked professionals who were friendly and interested in them – not just their condition. They liked established relationships where they were able to build up trust: *"You need continuity and you need a person who you can be friends with before you're going to tell them things."*

Good support

People received lots of different types of support: some people's parents did most of it; some had agency staff helping at home; some had personal assistants paid for with a direct payment. Young people said their ideal supporter/ carer would be quite close to their own age and someone who they could build up a relationship with over time. Trust and confidence were really important. One young man described an ideal carer: *"Someone you can joke with, someone who knows what they're doing and someone my mum can get on with."*

Chances to talk if/when they wanted or needed

When it comes to talking about Duchenne, there isn't just one way or answer – everyone's different. Some people don't want to talk about it at all while others want information from people they like and trust: *"No one's ever told me anything. I just sort of found out myself. I don't know if there is a way of finding anything out really."*

Time away from family

It's good for any family to spend time apart. *"You do spend a lot of time with your parents. I think sometimes it'd be nice to have a bit more time to myself and for my mum and dad to have a rest too."*

See Guide to transition for 13-25 year olds with muscle disease for further useful information and advice about social care and support. Chapter 26 discusses emotional support; chapter 27 covers peer support and chapter 28 covers sex and relationships. Contact the Muscular Dystrophy Campaign on 0800 652 6352 or info@muscular-dystrophy.org to order your free copy.

Want to find out more?

Liam and Craig: We hope this has been interesting. Here's some places you can find out more information. Remember, stay positive and keep trying. Good luck!

More information about transition

www.transitioninfonynetwork.org.uk includes information about:

- education
- employment – work and jobs
- free time
- health and wellbeing
- housing
- money
- relationships
- support
- transport and travel.

More information about Duchenne muscular dystrophy

- Muscular Dystrophy Campaign
– www.muscular-dystrophy.org
- Duchenne Family Support Group
– www.dfsg.org.uk
- Action Duchenne
– www.actionduchenne.org



More information by young people with md for young people with md

Trailblazers, the Muscular Dystrophy Campaign's network of young campaigners, was formed in 2008. *Trailblazers'* campaigners fight against the social injustices experienced by young people living with muscle disease or a related condition and work towards a world where having muscle disease or a related condition is not a barrier to accessing mainstream opportunities, facilities and services.



The *Trailblazers* work to ensure all young people with muscle disease can gain access to the education, employment and services they require, by carrying out investigations and reporting on their findings. They are building a UK-wide network of young people who campaign and raise awareness on issues that affect people with disabilities.

Joining *Trailblazers* gives young people with muscle disease the chance to develop new skills, make friends and campaign on issues that are important to them.

To become a *Trailblazer*, or order a copy of any of the *Trailblazers'* investigative reports contact **020 7803 4807**, write to **trailblazers@muscular-dystrophy.org** or visit **www.muscular-dystrophy.org/trailblazers**

"As well as having the chance to campaign on the things that are most important to me, Trailblazers gives me an opportunity to make friends with people who have similar interests. Trailblazers also gives me the chance to inform younger members of the group about the problems they might face, and to talk with the older members about what they found to be good tactics in all aspects of life.

It's been great to see this project develop into such a big network as it helps so many campaigners like myself to learn new skills which we'll all be able to use in the future." Judith Merry, Keele

This booklet summarises a report produced by David Abbott and Professor John Carpenter at Bristol University and signposts to the Muscular Dystrophy Campaign's Guide to transition for 13-25 year olds with muscle disease.

To receive a copy of either document, please contact us on 0800 652 6352 (freephone) or info@muscular-dystrophy.org

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