

Conversations about end of life with men with Duchenne muscular dystrophy

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with DMD Pathfinders

Funded by the Duchenne Forum



Three things

1. This may not be academic for you
2. There is very little I need to say
3. Who you gonna call?

With MD you know it's life limiting but it's hard to know what to do at the end as it keeps changing. As I got older I kept thinking about it more and more and I thought it's good to think about it but make sure you tell someone else because if you think about it too much yourself it's like, you get more depressed and you feel alone.

Cos to me death is upsetting but it's a natural thing. It's the fear that stops people talking about it. It comes down to having to accept it. You may even prolong your life a bit more if you can accept it and talk about it. You know, if you can get rid of your hurt and anger and depression about it. You can get on and have a more fulfilling life. That's why I think I have to talk about it. Cos I don't want to waste my life crying about the fact that I'm going to die. I used to be scared and I used to get a lot of physical symptoms like stomach issues and headaches and I couldn't breathe. Once I realised it was out of fear and anger and stress I kind of had to release that to improve my life.

With the health clinicians I've not really talked to them about dying. I've never talked to a consultant about it. Doctors say a lot when you're diagnosed – you won't be able to walk, you'll have to go into a wheelchair – then they suddenly stop when you come to death. It's odd really because they're leading you to the door of the conversation but they're keeping it closed which makes it more scary really. If a doctor can't talk about it and you don't have a close relationship with your parents when it comes to these type of issues then **who you gonna call?** I think the barriers is that they don't want to upset you but if the doctor does broach the subject then the patient might open up more.

If you can talk about how you live and the way you live then you can talk about dying. Talking about death isn't morbid but **it's difficult to talk about your death to someone who may not be that interested in your life.**

The study

- To report on 15 qualitative interviews under-taken with men with DMD regarding their views and experience of end of life planning
- Recruitment was via closed Facebook page by DMD Pathfinders
- 15 participants (age range 20-45)
- 9 living with family; 6 independently
- 4 Asian British, 11 White British
- Study limitations.

Why this study?

- Built on local clinical concerns and earlier feasibility study
- Advances in life expectancy for young men with DMD continue
- Research literature suggests end of life planning has significant benefits
- Recent DMD research revealed ‘minefield’ around what gets talked about when and by whom
- Lack of evidence about how/if men with DMD and their parents want these conversations.

Semi-structured interviews

- What conversations had taken place?
- What did they want to know?
- How do things get discussed outside the professional or clinical sphere?
- Is emotional/social care support available?
- What would a good conversation look like?

What conversations had taken place?

- No-one recounted discussions in paediatrics or in adulthood with a professional
- Majority had had discussions with respiratory consultants
- Pleased that these conversations had taken place, but they were limited, “over-medicalised” and not about end of life in the round (though likely mis-match).

He brought it up in a very matter of fact way. I don't think he spoke to me as a person. I felt like just a case. I am a person.

What did men want to know?

How does life tend to be when you get near to the end? I've asked that and they say, 'Don't know. Can't tell you.' Which doesn't really help.

All you really want to know is, like, is it painless, or you're asleep or something? Or would you suffer?

It's specific things you want to know about what is the last stage going to look like? Are you going to be gasping for breath and in pain and all sorts of horrible things? Or will it be potentially peaceful?

If someone dies suddenly, no-one ever speaks about it... but you want to know how they died. You want to know was it the MD, the heart, the lungs? You can't ask but you'd quite like to know.

What are the triggers? On many days it's not something people wanted to talk about...

- When friends die
- Linked with an acute episode; anxiety and depression
- Getting older.

With every milestone I've been thinking, 'Oh if I could just do this before I die,' kind of thing. And the list just keeps getting longer. I keep doing things and realise I'm not dead yet! But even with that in mind you still know that the next cold or chest infection could be the end, you've always got that in the back of your mind.

Other emotional and practical concerns including digital legacy

One thing that worries me is that people might not understand what I really want. I sometimes think about doing a will but I haven't got round to it.

The biggest thing I worry about is what happens to everyone else. It sounds weird but it's like if you die you're letting them down or something. I worry that they will be upset.

How's all your stuff taken care of afterwards? What happens to your stuff, your house? Do your family do the right things? Because that's my biggest fear about death. It's not the fact of me not being here, it's the issue of how do people carry on when I'm not.

Difficult family discussions

I don't really talk about it with my parents because I don't think they want or like to hear it. It's quite a sensitive thing isn't it.

.....I came home and I spoke to my mum. I asked her if I had a short life. She said yes but they didn't want me to think about dying, they just wanted me to be **positive** about life.

They probably don't realise we would want to have those conversations. Really everybody wants the same thing but it's that initial barrier, getting over that really.

Value of peer and on-line support

I always think it's easier to talk to lads with MD because they're in the same boat and they understand. There's always dark humour and stuff. Yeah we do talk about ourselves and stuff like end of life.

Availability of support?

- No one reported ongoing contact with social services.
- All of the men talked about being depressed and/or anxious at various points in their adult lives. Most had accessed counselling or psychology services. These had not routinely proved useful in exploring issues about DMD and end of life.
- Several men commented on the unavailability (and physical inaccessibility) of counselling and that it was rarely offered.
- One man had a psychologist who came to the house, '...every so often', but despite the fact that he wanted to talk about end of life issues, he had never brought it up:

I wouldn't like to bring it up with him. They would have to bring it up really for me to talk about it. Sometimes you just need a little prompt that'll help you bring it up. And then it's like an opening, which is good.

What would a good conversation look like?

- The provision of proactive cues:

To the doctors I'd say go for it really. Obviously be diplomatic and tactful but if you ask it the right way, you'll get the right response. Don't shy away from it because it's the most important decision, really. That's how I feel.

- Personable and expert:

The important thing is having the right discussion, not being gloomy but being honest. It needs to be credible because it [DMD] is life limiting, you can't hide from that either.

Avoid tragedy narrative, talk about death and then focus on living a good life

People need to be built up in positive ways. It's like, yes, people need to have these conversations so that you can move on and actually get on with your life. The focus should be on living with Duchenne and having a good life with it. And then obviously as part of that you need to think about death and dying and be able to get into a position where you can move on from it. **That's the only way it's cathartic, if you can then move on afterwards.**

I'm not here to tell you it's easy...



Excerpt 2 - R2 - P1 (2) 39:16

01 R2: okay alright um finally um- no not quite finally on
02 this section but um- (1.5) °penultimately° erm (1.0)
03 there's even th- even more question (0.6) more ma-
04 personal question of (0.2) well having sex with
05 yourself if you understand what I mean by that
06 (0.5)

07 P1: wanking

See e.g. Pino, Marco, Ruth Parry, Victoria Land, Christina Faull, Luke Feathers, and Jane Seymour. "Engaging terminally ill patients in end of life talk: how experienced palliative medicine doctors navigate the dilemma of promoting discussions about dying." PloS one 11, no. 5 (2016): e0156174.

What was it like taking part in the research?

I actually enjoyed talking about it.

I could talk to you about this all day. I think it's healthy to do this study.

The questions weren't too hard and I think it helps that you've been and talked to other ones with the same condition. You kind of know what they're talking about.

Really it's been a bit more positive than I thought, because I thought, God, we're going to have to talk a lot about death... But I suppose it's not about that, it's about sort of thinking ahead, towards...well how do I plan for the inevitable?

Thank you for listening and thank you to our participants and funder.

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Abbott, D., Prescott, H., Forbes, K., Fraser, J., & Majumdar, A. (2017). Men with Duchenne muscular dystrophy and end of life planning. *Neuromuscular Disorders*, 27(1), 38-44.

Linked outputs:

- Jepson, M., Abbott, D. & Hastie, J. (2015) "This Is Another Personal Question": Research Interviews and Discussing Sensitive Issues with Men with Life-Limiting Conditions." *International Journal of Men's Health*. 14 (3) 273-286.
- Abbott, D., Jepson, M. & Hastie, J. (2015) Men living with long term conditions: exploring gender and improving social care. *Health & Social Care in the Community*. 24 (4) 420-427.
- Abbott, D. & Carpenter, J. (2015) 'The things that are inside of you are horrible': Children and young men with Duchenne muscular dystrophy talk about the impact of living with a long term condition. *Child Care in Practice*, 21 (1) 67-77.
- Abbott, D. & Carpenter, J. (2014) 'Wasting precious time': Young men with Duchenne muscular dystrophy negotiate the transition to adulthood. *Disability & Society*, 29 (8) 1192-1205
- Abbott, D. (2012). Other voices, other rooms: reflections on talking to young men with Duchenne muscular dystrophy and their families about transition to adulthood. *Children & Society*, 26 (3) 241-250.