“It’s complicated”

*Trailblazers’ investigation into disability and relationships*

Report 15 of the Inclusion Now Series February 2014
About **Trailblazers**

*Trailblazers* is a group of disabled campaigners from across the UK who tackle the social issues affecting young disabled people, such as access to higher education, employment, and social and leisure opportunities. We aim to fight these social injustices experienced by young disabled people and to ensure they can gain access to the services they require.

We are part of the Muscular Dystrophy Campaign.

About the Muscular Dystrophy Campaign

The Muscular Dystrophy Campaign is the leading UK charity fighting muscle-wasting conditions. We are dedicated to beating muscular dystrophy and related neuromuscular conditions by finding treatments and cures and to improving the lives of everyone affected by them.

Our work has five main focus areas:

- we fund world-class research to find effective treatments and cures
- we provide practical information, advice and emotional support for individuals with muscle-wasting conditions, their carers and families
- we campaign to bring about change and raise awareness of muscular dystrophy and related neuromuscular conditions
- we award grants towards the cost of specialist equipment, such as powered wheelchairs
- we provide specialist education and development for health professionals.

This investigation has been researched and compiled by the following *Trailblazers* ambassadors:

Frances Ashe – Northern Ireland
Jessica Berry – North West
Sean Fitzsimmons – Northern Ireland
Zoë Hallam – South East
Michaela Hollywood – Northern Ireland
Martin Hywood – South East
Sulaiman Khan – London
Anthony Price – South East
Mathy Selvakumaran – Midlands
Carl Tilson – North West
Robert Watson – Scotland
Introduction

Exploring personal relationships is a natural part of growing up for young people, and this is no different for a young disabled person. Trailblazers wanted to consider personal perceptions of disability and relationships through case studies, surveys and the sharing of personal experiences.

This investigation aims to present these sensitive and private thoughts in an honest and realistic way to provide a matter-of-fact account of what it really means to be single, in a relationship or married, when you have a disability. The report will reveal, through Trailblazers’ own words, the complications, worries and positive stories to demonstrate a wide range of experiences when attempting to build intimate relationships.

Owing to the sensitive nature of the subject, we gave Trailblazers the option to remain anonymous. We believe this has enabled some young disabled people to give a deeper, more realistic expression of their thoughts on intimacy.
How would you meet?

Many young people today form relationships online; others prefer to get to know people as friends at work, university or in social situations. As for any non-disabled person, there is no one approach that works, it always depends on what you are comfortable with and feel safe doing. Finding some common ground and feeling relaxed in someone’s company is often initially helpful. Confidence, staying positive and being honest in any situation can help, but this takes time.

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**Trailblazer Sean Fitzsimmons and his partner Lianne got married last summer. They share their story of how they met.**

**Sean:**

“I first met Lianne while studying for our PGCE in Primary Education at the University of Aberdeen. I have always been a very confident person and have many female friends. I was very conscious, however, when starting my course that there weren't too many guys who looked like me. I think initially I was very keen to assure Lianne that any fears or concerns that she may have in relation to my disability could be overcome. In reality any fears I had were quickly dispelled; Lianne liked me and my disability didn't really come into it. It was very refreshing to meet someone with such an open mind.

“I think it fair to say that all our family and friends have been entirely supportive. The fact that neither of us takes ourselves too seriously helps a lot – life is way too short! A number of our friends have been keen to know more about my condition and I think a few of them initially were afraid to ask for fear of offending me. They approached Lianne in my absence and I can completely understand this. It's nice to be able to have open conversations around disability, but it's finding a balance – whilst some people (like me) are more than happy to have an open and frank discussion, others may wish to keep their condition private. I think people can only judge where a person stands after knowing them for a period of time.

“Whilst I have experienced negativity in the past as an individual, I'm thankful to say that we haven't as a couple to date. The odd surprised look on nights out perhaps but we do not let it bother us.
“Honestly, having a disability can be a big consideration. If you love a person their disability should not be an issue, however simply ignoring the fact they have one or not being aware of the challenges this might present you or them could create difficulties. It's important to be open and honest from the outset – there is no point in having concerns and not voicing them.

“The issue of disability crosses into a lot of areas (finance, family, where to live etc) and while it's important to be conscious of this we feel it important to never let it dominate our decisions. We take chances, if we fall flat on our faces doing so - we'll pick ourselves up and try again!

“A big question that plays on people’s minds when it comes to relationships and dating is do disabled people have sex? Disabled people are just as capable of leading an active and fulfilling sex life as anyone else. I feel it is important that this is conveyed - growing up with a disability can be isolating for some and breaking down stereotypes and commonly held misconceptions is an important step in ensuring less people are 'overlooked'."

Lianne:

“I think initially it was obvious that the issue of disability was more of a concern for Sean than me. Being a typical male, Sean did not want to fall into the 'friend zone'. It didn't matter to me at all and, because Sean didn't make it an issue, I didn't see it as one. Don't be afraid to chat to someone with a disability. There is a great deal of pressure in today's society to look a certain way and fit a certain mould. If you take time to get to know someone with a disability, you'll very quickly realise they are just like everybody else, they have the same hopes, fears, desires and dreams. Individuals can be afraid to challenge convention and dating someone with a disability can be viewed as taboo – largely because they fear they might miss out on something 'in the bedroom'. This couldn't be further from the truth.”

What other Trailblazers say about meeting people

"Disability events are not the only way to find relationships, but personally – rightly or wrongly – I ‘gave up’ on able-bodied guys giving me a second look. When I played powerchair football for my first season, I was excited to see if there would be any hot disabled guys there! By some luck, coincidence or some may say 'fate' I met my current partner who as cheesy as it sounds is ‘the one’. I have never had an immediate attraction to someone – able-bodied or disabled – as I did to him."

"I don't like meet new people in a public place because I would feel less safe. I would never date someone I met on the internet (but that's not really to do with my disability, I just don't like the idea). I like it when my disability is known from the beginning. The first words said, and the immediate reaction to a disabled person, are a good screening mechanism to find good guys!"

"By being online, I am able to meet people without my usual nerves! I am also able to form stronger relationships. When I do meet people in person I am usually more confident – even though I'm often still a nervous wreck! My online friendships are extremely strong and I know without those people in my life from around the world I would be isolated."

"I am lucky to meet new people because of my career. It's a necessity and forces me to overcome any personal fears or anxieties."
“[I meet people] definitely through dating sites or social media, because you can strike up conversations and get to know each other much easier than in pubs or clubs where it’s too noisy and most people are too drunk! Also if you choose to, you can get to know the person first before you disclose your disability, and I prefer this approach so that I can get to know the girl first and see how we get on. If she gets to know me first, then hopefully she won’t then be scared off by the disability. But unfortunately this approach isn’t always successful, as I have found out.”

“I would feel uncomfortable meeting strangers in bars/etc. with my disability. I would prefer to meet someone that I sort of knew (or know through people who know me). At least meeting someone at university, you have that something in common.”

“I think it is easier when you get to know someone properly first. It removes the ‘see-the-wheels-not-the-person’ attitude.”

**Trailblazer Fran Ashe lives in Northern Ireland with her husband Alan and their young daughter.**

“Alan and I met on holiday in Magaluf; I was 18 and it was my first girlie holiday. He was from Belfast and I was from Streatham in London. After our holiday, we went back to our homes and we just visited each other long-distance for about a year. I was in the process of applying for university and so one of the places I put down was Ulster-based Jordanstown. I decided to go there and study business and finance. I moved into a flat with Alan, who had never known anyone with a disability before – he was just open-minded!

"I fell pregnant in my last year of university. It wasn’t something that was on the agenda, I was 23 and I wasn’t married at the time, it was my final year. I was 11 weeks pregnant when I found out, and I had my first scan on the first day of my first final exams. I’d worked hard, so I just got on with it. It was more shock than anything, and I didn’t really have any time to process it until after my exams! When I had my graduation, I was four months pregnant. I think the first thing that played on my mind was whether I could pass on my muscular dystrophy. Our baby has got muscular dystrophy but that just means we have more things to juggle. I would recommend every 18 to 30-year-old woman to have at least one girlie holiday; it was one of the best experiences I have ever had alongside university. And a holiday romance – or in my case lifelong romance – just added that wee something!”

**Zoë Hallam and her boyfriend, Will, share some honest thoughts.**

**Zoë:**

“I would be the first person to put my hands up and admit that I’m pretty inexperienced in the dating game. I met my boyfriend, Will, at university, and we were friends long before the idea of being anything more than that occurred to either
of us. In a way that meant that the first (and often the most seemingly insurmountable) hurdle of being in a relationship – meeting your prospective partner – was removed from our way. It also – so I hoped – allowed him to form a reasonable idea of what he might be letting himself in for by being in a relationship with me – both in terms of my disability but also my personality, which arguably isn’t for everyone! Still, I worried a fair amount in the early days of our relationship about ‘ambushing’ him with the large collection of things I was unable to do myself and the sheer amount of extra support I required, which I’d successfully kept under wraps in the course of our friendship in order to maintain a veneer of independence in polite company. It became a toss-up: when we were spending time together and I needed the loo, did I ask him to help me, or did I call my carer down from her room to assist me instead? At what point would it be appropriate to ask him for help with getting dressed in the morning, or showering?

“We’ve been together for three and a half years now, and the whole way through our relationship has been something of a balancing act. You can’t ignore the fact that I’m disabled, as it permeates through pretty much everything we do to some extent. However, we are both generally able to take any obstacles in our stride and have become pretty good at predicting where things might get difficult. It’s been a learning experience for both of us. Aside from my employed PAs, and since we moved in together after university, Will’s taken over from my parents as my primary caregiver, and that’s been an adjustment that hasn’t always been easy. I’ve had to learn that he’s not a mind-reader, and can’t always tell when I need help with something!

“It can be difficult managing the relationship when I also have a live-in carer, upon whom I rely for most of my care. Having a relative stranger come into the bedroom in the morning and help me get dressed can’t have been an easy thing for him to get used to. Similarly it can be difficult to inject much spontaneity into our relationship as so much has to be planned in advance and can’t be managed by myself independently. I know he wishes that I could be a bit more impulsive, but that’s not solely due to my disability, and I think there are a lot of able-bodied couples who experience the same thing!

"Because I’m so dependent on him, we try and remain independent in whatever other areas we can. If we go to a party together we tend to spend most of the time apart and are often content to amuse ourselves individually at home. It’s important to keep that element of personal space when so much of what we do together involves him helping me. To try and equalise the relationship I keeping track of utilities and bills, booking trips and holidays, managing our social calendar – all of that is my domain. It helps us both feel like we’re more like equal partners.

“There are still challenges ahead. We want to buy a house together, properly settle down, but with both of us working it’s difficult to get the financial support we need to make that a reality. The main thing is though that we are both able to support each other, and feel like we can rely on each other to overcome whatever life throws at us. And at the end of the day, that makes us no different from any other couple starting out on their lives together. Long may it continue!’
Will:

“‘But what will you do for your first dance?’ This was one of my mum’s puzzled observations during our discussions about Zoë’s disability. Now as a 23-year-old juggling the intricacies of an early career, flats and whether to get the new PS4 or Xbox One, marriage feels to me about as relevant as retirement. But there is a useful point to take away from mum’s concern: my relationship with Zoë throws up certain difficulties which necessitate a degree of thought, planning and patience. My relationship is a fantastic, edifying part of my life which I would not change for anything and I would urge practically everyone to disregard disability as an impediment to a happy and fulfilled love life.

"But (and cheesy sentences like that are always followed by ‘buts’) going out with a disabled person does affect many aspects of your life. The first, and which for me was the most jarring, is the issue of care. As a wheelchair user it makes sense for Zoë to have a live-in carer. We both work in London – she is starting a new job at a charity; I’m an analyst at a promotional organisation for the city – so we leave and get home at different times of the day. I can’t, and for the sake of our relationship won’t, take on full care responsibilities, so this means having someone live with us to deal with Zoë’s day-to-day needs. For someone who hasn’t experienced this dynamic it appears very strange, though people rarely push me on it. In fact, after some adjustment, it is empowering: Zoë’s carer acts as a proxy for her, with us sharing tasks as Zoë and I would if she was not disabled. Of course, there is the issue of personal space; we resolve this by having a carer only in the week, when we’re working anyway, and I help Zoë with her care needs at weekends.

"This brings me to the second point I’d like to make: the practical elements. Some of them are physical, e.g. lifting. At this stage this is not too much of a problem – I have, for want of a better term, hauled Zoë up to the third floor of a house in Clapham, the stone steps of a national memorial in Spain and the tops of more cinema auditoriums than I care to remember. There are limits, however. Not only will I not be able to do this with quite as much gusto forever, but some places will always be inaccessible – a romantic trip to Venezuela’s rainforests or the Parisian Catacombs is never going to be on the cards.

"Equally, if not more importantly, are the financial implications of our relationship, my final point. As I said at the outset, going out with someone in a wheelchair requires communication and planning to address upcoming challenges. I think this is inherently a good thing in relationships anyway but it is especially important for us faced as we are by the extra challenges arising from disability. The additional rent arising from an extra bedroom for Zoë’s carer, combined with the problem of inaccessible housing in London’s less affluent areas, has forced us into central London.

"After many centuries of saving, when we can afford a place of our own, we will probably need to make a number of adaptations. As disabled readers will appreciate, sticking ‘accessible’ on the product’s description also sticks a great deal of inaccessibility on to its price. With careful planning, however, we will hopefully overcome this problem. On the other hand, though, the opportunity for me to get in free almost anywhere Zoë goes (as her carer) does ease the financial burden and allow for an exciting social life!

"My experiences in a relationship with someone with a disability are not, of course, universal. But I do think the care needs, practical consequences and financial
implications are relevant considerations for anyone embarking on such a relationship. They create challenges, certainly, but with some thought, planning and communication they can definitely be overcome.”

**Martin Hywood is 40 years old. He took the time to share his story with Trailblazers demonstrating that relationships can last long term.**

**Martin:**

“I met Michelle when I was 19 and I was a customer at a bar that she was working at as a waitress. I was determined to get her attention and after asking a few times she eventually agreed to go out on a date. Now I am 40 and we have two children together, so my pestering was definitely worth it!

“When I first met Michelle I had not been diagnosed with muscular dystrophy and it wasn’t until one day that I fell over at work and hurt my knee that alarm bells started ringing. This is because my injury just wasn’t healing at the pace it should have been. I underwent tests and was eventually diagnosed with limb girdle muscular dystrophy when I was 23.

“It really worried me how everyone would react to my diagnosis and particularly how it would affect my and Michelle’s relationship. However, I am very fortunate to have a fantastic group of family and friends around me and Michelle was the greatest support I could have hoped for. From the very beginning Michelle took on my diagnosis like it was her own and said that no matter what, we were a team and would overcome everything together.

“A lot of my strength and determination comes from her support and resolve that this was a joint challenge to bear. We have had to adapt some aspects of our life but change is something all couples have to deal with, for us the change was adapting to life with muscular dystrophy. What will never change however is how we feel about one another, every aspect of my life goes through Michelle and we tackle everything as we always have, as a team.

“Not only has Michelle been an emotional support but she has been a physical support and this has been one of the changes we have experienced. For example I wanted to keep as mobile as possible and so I often lean on Michelle while I walk in order to keep my balance. We always communicate about how my condition is developing so that we can discuss how to adapt things.

“My limb girdle muscular dystrophy has also affected my relationship with the children in some ways as I don’t have the physical ability for the livelier playtime activities or the ones where you need to be at floor level, like with Lego. Both my young daughters are aware of my condition and are helpful and considerate. Even the youngest one, at three years old, understands my limits and is supportive in
her own way; it is very endearing. I also have a now grown-up daughter of 21, from a previous relationship. She has recently found out that she is a manifesting carrier of muscular dystrophy and at first I felt guilty that this was something I had passed on. However Lucie has shown the same support and resolve that Michelle has towards my diagnosis and I could not be more impressed with her.

“In some ways my diagnosis made my relationship with Michelle stronger and it threw up many challenges as my condition developed. Sometimes I feel like we would not have been this strong if I had not been diagnosed – it has made us look out for each other more.

“Michelle has not let my disability change the way she feels about me and I feel that the diagnosis certainly gave us a challenge but it has not affected us as a couple. I would say to anyone who has a disability that I really believe there is someone for everyone. If someone does not love you for who you are, it is not meant to be. Having a disability doesn’t matter, it is a physical feature of someone for sure but it does not dictate their personality and everyone, regardless of ability, is entitled to a happy relationship.

**Michelle:**

“Of course each day is a different challenge and some days are easier than others. Martin and I will deal with everything as a team and I would take 10 bad days for one good day because our relationship is worth every second.”
Perception

What people think about themselves can affect the way they behave, but it is important to remember that what a person believes about himself or herself isn’t necessarily true. Forming relationships can be difficult for any young person; lacking in confidence and feeling uncertain is normal. What people should remember is that others have similar thoughts about themselves.

Physical aspects of relationships, getting out and meeting people, can all be challenges to developing relationships, and will affect your perception. However, nothing is impossible. Many disabled people have fulfilled lives, and have developed personal relationships.

Three-quarters of Trailblazers believed that other people’s opinions are an obstacle to forming a relationship.

Nine out of 10 said that they would feel more confident about dating if other people were more open-minded.

East Midlands Trailblazer Mathy Selvakumaran shares her thoughts on disability and dating. Mathy is currently studying for a Phd at Sheffield University:

“Sometimes I think that I'm making this up in my head, but I still feel like people 'judge' me and my date-ability based on my disability. My friends would never say my disability has come between our friendship, but it seems to me as if having a disability has precluded me from having the status of being 'attractive', both according to society and in my own life. In some people's eyes it does make me 'undateable'. In an ideal world people would be judged on the quality of their character as opposed to their appearance, but when considering relationships I think a lot of people still hold this preconceived notion of beauty in their heads (one that more often than not centres around a physically able body, amongst other things) that excludes disability from ever being attractive.

"Also, I think that on a more practical level disability can prevent young people from being in the position of starting a relationship. If someone can't put themselves into those sorts of social situations where people their age can find a date, then it becomes a lot more difficult.

"I feel like people foreground physical impairments when they first meet a person with a physical disability, whether subconsciously or not. This applies to any sort of situation – sometimes you can feel as if your disability is the elephant in the room, hanging over situations and remaining unmentioned for fear of making the encounter uncomfortable. Especially when it comes to those 'romantic' situations where you're getting to know someone, sometimes it seems like people put the disability before the person. The last thing you want, in those sorts of situations, is to feel subconscious about the fact that your disability seems obvious! But at the same time you do wonder if the reason you feel subconscious about your disability is because people see the disability before you as a person.
"People might say that personality is more important than physical appearances, but the truth of the matter is that disability can act as a bit of a barrier, and I think that some people can be hesitant to pursue a relationship with a person with a disability (whether they would admit it or not). Disability kind of becomes used as an excuse for not dating someone. Just as if someone would say 'I would find them attractive if they didn't smoke', with a disability there's a suggestion of, 'I would find that person attractive...if it weren't for the disability'. In that way, I feel like my disability prevents me from forming relationships."

**What other Trailblazers say about perception**

"I don't believe I'm seen as attractive."

“I am 18 and paralysed from the upper chest down. Able-bodied guys my age don’t look at me twice. I am happy in a relationship with a guy with muscular dystrophy and I have never been happier but it goes without saying; I believe we are limited in our relationships due to our disabilities.”

“I think it makes a lot of people view you differently. I wouldn't necessarily say this is a barrier (my boyfriend obviously didn't care) but I would say it changes things. Some people simply aren't interested in a girl in a wheelchair.”

"In itself, it can make it difficult – not necessarily prevent – forming relationships. If someone doesn't want to form a relationship with me based on my disability then they're probably someone I shouldn't be hanging around with.”

“I find it hard to tell people about it especially if they are someone that I fancy because I think that it will put them off. I believe that people will not find me attractive because of my disability.”

“I wouldn't go as far as to say it prevents meeting people, but it definitely makes it a lot harder. Most people just see my wheelchair and my bipap mask and it scares them away. They don't see me, don't get to know me.”

“Lack of confidence is a barrier for me, and it is hard when you have 24/7 care – as there is not much privacy.”

“I find girls think that I'm going to break, or something.”

"It takes a little longer to break through people's pre-conceptions but it's not impossible to do so.”
A perspective on intimacy

Sex and disability is something of a taboo subject. However, as in any relationship, it is an important area to explore. In some situations, people are looking for intimacy without necessarily a relationship, fulfilling physical desires rather than emotional ones.

North West Trailblazer Carl Tilson shares his frank experience with a sex surrogate.

"People like me do not have an active sex life or don't need one because I'm disabled.'

"That is in truth to me what society believes, that we as disabled people are not able to enjoy sex. I'm 26 years old living with Duchenne muscular dystrophy, which is a condition that slowly weakens and deteriorates voluntary muscle strength. This may surprise ‘society' but disabled people can have sex; we just have to be more creative in our approach. Since I was legally able to I always wanted to experience sex, and around three years ago it was my choice to hire an escort to lose my virginity so I discussed it with my parents. Luckily I have a great relationship with them and they were very supportive of my decision.

As a disabled person there are limitations but there are ways around it. I did some research on the Internet about escorts; I read through many websites and finally found one I thought was suitable. I pre-arranged with my parents and they agreed to go out for the evening and leave me with my care assistant waiting for the escort to come over.

The escort arrived and she was dressed very smartly and discreetly; she didn't bring any unwanted attention to herself on the street. She was welcomed by my care assistant and I was already hoisted on my bed before she came. Then she asked me where she could get ready and asked permission to get ready in my bathroom, so I said, ‘Yes!’. Then when she came out all ready for the experience, she reassured me she would take it slow and wouldn't do anything without my permission. Then she asked me my likes, dislikes and what things I wanted to experience.

The escort I had was very caring and was very professional; she even kept trying to make me laugh as she had a great sense of humour that put me at ease. Then after we were finished we had a little hug and a little chat. I think it's important to explore your sexual aspirations and it's only natural to experience sex. I felt a boost of confidence and it helped my self-esteem. The only downside of hiring an escort is you don't have that closeness as you would have in a relationship.'
Three out of four Trailblazers feel that the issue of disability and relationships has not been represented accurately in the media.

When asked whether recent programmes on disability and dating show a realistic representation of disabled people, this is how Trailblazers responded:

"I feel these programmes show only the extremes and typically negative aspects. My partner and I met by coincidence, in just the same way anyone else would, and kicked it off immediately as people due to personality and attraction, once again the same as anyone else. I feel the media portrays an inability for disabled people to have balanced 'normal' relationships.

"I would go as far to say my partner and I are the most 'normal' balanced couple of any couple of my age group I know, disabled or not. We are not together because of our disabilities, we are together because we are attracted to each other both physically and emotionally. We didn't even discuss the subject of our disabilities and the reason for us both being in chairs until weeks down the line of talking to each other. I think the media should show the normality of the situation and show normal balanced relationships to give perspective."

"No – but then what is an accurate way? Every relationship is different. I suppose it's never possible to get the full picture, just more examples of different views. The Sex Ed Show section on disabled people was one I really liked though."

"I believe Channel 4 has gone some way in initiating the conversation – but they have yet to actually be accurate. While many people in The Undateables use dating agencies which specialise in disabilities, I believe that all aspects of our lives should be integrated – relationships included, unless love may never strike!"

"I feel they have only touched upon one aspect of disability and relationships and it is still too much of the surface; the media needs to delve further. As it stands, shows like The Undateables simply propagate the notion that if you have a disability you should only date your own kind. This is wrong and needs to be stopped. A person isn't a disability – it is only an aspect of their life. There is so much more to an identity than the physical."

"I feel they have done some good but I do think the 'freak show' element [of shows like The Undateables] attracted the wrong audience."

"It is too sensationalist and patronising."

"With some cases they show extremes, which aren't really reflective of the majority of people's experiences."

"In my opinion these shows are really voyeuristic and make a 'freak show' of people with disabilities dating. Yes, some people will say that shows like these are 'empowering' for people with disabilities, and yes, they pick people that they think will

1 Channel 4’s ‘The Sex Education Show’, has featured disabled couples.
2 Channel 4’s ‘The Undateables’ follows the stories of several disabled people looking for a relationship.
make good ratings, but at the same time it suggests that everyone with a disability has the same sort of (weird, freakish) love life.”

“I don't think it helps integration. The television producers might think it is equality and showing the world we’re like everyone else but I think it does the exact opposite, it puts us in the spotlight more and I don’t think the name *The Undateables* does us any favours.”

“There seems to be minimal portrayal of disabled people in long-term, stable relationships, and that's frustrating.”

“The portrayal of people with disabilities in the media is appalling. No-one wants to have open and frank discussions about sex and disability, and when they do it’s by means of pity. Sex is an important part of a relationship, and should be addressed. Many people may feel they cannot have a loving and sexual relationship with someone because of their disability.

“Having people with disabilities who are married, etc. talk to younger people would help so many. We need people who can be honest, who aren’t embarrassed and can speak truthfully and openly about these complex issues.”

“There’s still a stigma surrounding a disabled person which is hard to waive. I have found that people are more open to disabled partners if they already have disabled friends, as there’s a level of understanding there. Disabled people need to be seen more, and that's partially our own responsibility. However the media and infrastructure can massively help or hinder any efforts to this end.”

*London Trailblazer Sulaiman Khan gives an honest account of his experience looking for a relationship*

“It is very difficult for me to form relationships, as meeting people is hard when you are a severely disabled wheelchair user. I find this is often due to the complexities of accessibility and logistics of meeting people spontaneously. Not to mention that it is hard to go anywhere without my support workers, making it even more challenging to form relationships. Also, despite being fearless and very comfortable going up to people to say hello, I am concerned that the opposite sex may feel sorry for me and not see me as relationship material - the fear seems to take over. I strongly feel people often cannot see past my wheelchair, rather than the hard-working, interesting and humorous person that I am.

“Not only do I have the challenge of finding someone who will accept my disability, coming from a South East Asian background I am expected to find someone from the same culture. Although my family and friends have their own beliefs, I think if you are happy with someone that is what is most important; it wouldn’t matter for me if they have a different background so long as they accept me for who I am.

“I am also concerned about, if I do somehow form a relationship and wish to
have children with that person, what the probability of me being a genetic carrier of neuromuscular disease is. A doctor told me years ago that my siblings have a 66 percent probability of being a carrier. People may use this as a reason not to form relationships with disabled people. However, a lot has changed from the past and new treatments (and knowledge about genetics) may be available but more needs to be done to inform disabled people like myself of what the reality is; even if that's just providing information and greater understanding.

“Quite often the media tries to show what is ‘acceptable’ in disability dating, but it usually ends up showing people who are having difficulty and are classed as ‘undateable’ or ‘freaks’. This is wrong. I truly feel that just because you're disabled it doesn't mean that there is anything wrong with you. On the other hand, I feel that able-bodied people should not be frowned upon or thought of taking advantage when in a relationship with a disabled person as well. Society finds it hard to accept anything they don't understand, but if disabled people are able and wish to form a relationship they should be supported to do so.

“This is where I think the creative industries (filmmakers, directors, writers, artists and designers, for example) can have a huge positive impact in changing the media and general public's attitude towards disabled people who want to form relationships. Also, I think it is fine for some disabled people to say they want to have a relationship with a sex worker or something (which the media seems keen to highlight), as they're finding it hard to form relationships. Personally, I would prefer not to do this because I don't think it's a healthy way to build a relationship. I would rather meet someone who I can share my life with. It is society and the media that needs to accept that as a disabled person I have as much right to fall in love and form a relationship as my peers too. To conclude, I think, there needs to be more awareness with regards to disabled people, dating and relationships.”
Online dating

This can be a really great way of meeting people, in a non-judgmental environment. Access is equal for everyone regardless of physical challenges, you can also share aspects of your personality which may not be discussed in a normal social environment.

Over half of Trailblazers who responded said the easiest way to meet someone was online. Two thirds said they would reveal their disability from the start of communication with someone online

“If I were to start online dating, I'd share this from the outset. There's no reason to hide my disability because I would rather know upfront if someone doesn't want to date me because I'm disabled. Personally, I believe that trust is basis of every relationship.”

“I would mention it if and when it came up by coincidence, if he asked me my hobbies I would say I play wheelchair football. And if he asked if I was in a chair I would say yes. And if he asked any other questions I would happily answer them as we were getting to know each other. But I would never offer it myself as I don't think it is an important aspect of myself.”

“I think it's better that they have the full picture so you can see if they seem alright with it from the beginning. I think that's better than leaving it until you've got to know each other a bit, and then dropping the news (so to speak). If they have an issue with it, the whole thing could get messy!”

“My disability is a pretty prominent feature of my life so I would talk about it early on. However I would prefer it not to be the very first thing someone learns about me.”

“I don't know when I would reveal it – if you say it from the start you might attract the weird people who have disability fetishes, but at the same time I would hate to have to hide who I was for the sole purpose of finding someone online.”

“I always struggle with telling someone about my disability but I try to tell them as soon as I can because otherwise I feel like I'm lying to them. However I also don't like telling people about my disability because sometimes I feel like it changes that person's perception of me. I'm normal too; I just need some more support.”

“I believe if anyone is worth knowing they will accept the disability as part of the person – SMA is very much a part of who I am and that should not change because of a relationship.”

Trailblazer Robert Watson from Scotland, who has been dating online for a few years, shares his ups and downs:

"I have been dating online for at least seven or eight years. I feel it is a much easier way for someone with Duchenne muscular dystrophy like me, who finds it impossible to speak loud enough to have a proper conversation and get to know people in traditional (noisy) meeting places such as pubs and night clubs, to meet a potential partner."
“I have experienced both the positive and the negative sides of online dating. Although I am still looking for a ‘proper’ girlfriend, I have made one very good companion thanks to online dating. About three and a half years ago I came across the profile of a girl I liked the look of, who also happened to live in the same town as me which made it even better. I wrote her a message which she replied to quite quickly. We sent a few messages back and forth then we started chatting regularly. This went on for about a month until I felt we knew each other enough to meet in person for the first time. We were both nervous about it as neither of us had ever done anything like this before and so we agreed to meet in the local park, a very public, open place, just to be safe! As soon as we met, we started chatting and seemed to hit it off straight away. We chatted for a couple of hours before we each headed back home.

“After this good start we developed a very strong friendship. We went on walks together, went to the cinema, bowling, restaurants and she would come over to my house to chat and we’d watch DVDs together. I felt things were going well, but I still wasn’t sure; could I officially say we were boyfriend and girlfriend yet? So about nine months after we first met, I built up the courage to ask her about this. It turned out she just wanted to be good friends, and wasn’t ready for a full relationship with anybody yet. And still to this day she doesn’t have a boyfriend, so at least she wasn’t just saying that as an excuse. Now, a few years on, we are still very good friends and have been to many places together, so if it wasn’t for online dating websites I would never have met such a great friend.

“She is the only girl I have met in person thanks to online dating, but I have made a few ‘virtual’ friendships too – people I have emailed who replied to me and then we have kept in contact and we have got to know each other quite well. But alas, a girlfriend still eludes me! I will never give up trying, you can be sure of that.

“Now for the flipside: the most frustrating thing for me is, I feel I get little return for the amount of effort I put in. The other downside, which I hate even more, is when I have messaged a girl, she replies to me enthusiastically and we message for a week or two and I think great, things are going really well but then she just stops replying to me. The reason this happens to me I think, is because I don’t mention my disability in my online dating profile. I only put up pictures that you can’t really see my wheelchair in, because I fear if people see that I’m disabled it will put them off. I like to get to know the person first, and then if we are getting on really well and they seem to like me I will then tell them, in the hope that because they now like me it won’t matter to them that I’m disabled because they now know what I’m like.

“But unfortunately, with many people I have found this isn’t the case. They either just stop responding completely or come up with some excuse as to why they suddenly think I am not their type. Maybe it is the fear of the unknown for them, wondering what they would be getting into, being in a relationship with someone who is severely disabled, but other people are probably just ignorant.
“Some of my friends take a different approach – they are upfront about their disability from the very start, talking about it on their profile and not hiding anything in their photos. They feel this way you will know that those who message you are genuinely interested in you, they want to get to know you even though you are disabled, and this saves you from wasting a lot of time on people who will just run a mile in the opposite direction as soon as they find out that you are disabled, also saving you from all the hurt and disappointment as well.”

**South East Trailblazer Anthony Price tells us about his experiences of dating online:**

“In a world where people have very little time to go out and socialise, more and more are turning to the Internet in an attempt to find their ideal partner. I too was one of those people, but needless to say, my experience wasn’t a great one.

“Being the skinflint that I am, I opted for the free-to-use dating website. I filled out the profile, added my picture, took the test to find my ideal match, and then I waited. And waited. Then waited a little bit more. I received not one single message from anyone in two weeks, so I decided to take the initiative by sending out messages to people that I supposedly had a match with. Very rarely did the people reply, meaning most of the time I was just getting ignored. Occasionally I would strike up a conversation with someone, but it never went anywhere. This pattern of being ignored and getting nowhere went on for over a year before I gave up.

“I have many theories as to why I didn’t get anywhere. From the outset I declared that I had a disability; after all, there’s no point hiding it if you’re planning on meeting them anyway. I think we live in a world where too many people put too much emphasis on body image and having the perfect physique. Competition is fierce in the world of online dating and there are lots of men out there showing off bulging muscles and perfectly formed abs, something I’ll never have to offer. I also think it stems from a lack of awareness. In my opinion, people didn’t bother to get to know me because they’d already made up their mind when they saw the word disability in my profile. They just don’t know how to handle it, or react to it.

“Having said all that, I’m sure there are some positive experiences out there. For disabled people that can’t get to the pubs and clubs, or are too shy to go, it’s the perfect platform to reach out to people and maybe find a connection. I know from my own experiences that it can be difficult to strike up a conversation with someone in a pub, or club. They’re so loud and wheelchairs are so low to the ground, it can often be hard to get someone’s attention because they can’t hear you. In cases like that, online dating is perfect. It just didn’t work for me.”
North West Trailblazer Jessica Berry and her partner Matt met online, and in December 2013 had their daughter, Holly. Here's their experience.

Jessica:

“My boyfriend, Matt, and I have been together for just over 14 months. We met a month or so before we got together after both being members of a free dating website. Online dating had never appealed to me much, but taking into account having both a disability and a young son, the idea seemed like an ‘easy’ and ‘fun’ option at the time. I’d not long come out of a long-term relationship, so something serious wasn’t something I was looking for.

“Originally when I joined the site, I never mentioned my disability and I made sure that all my photos didn’t give it away either. However I was finding that the more I spoke to potential dates, a good 50 percent were put off by the ‘reveal’. After a few weeks I got fed up with the pressure of knowing that I would eventually need to find a way to ‘break the news’ before I could know for certain whether things were heading anywhere. So a couple of months later, when Matt got in touch, he never even mentioned the fact that my profile said I had a disability and used a wheelchair … so neither did I.

“From then on we were always texting each other and chatting on Skype. I could tell there was a definite spark between us, so a couple of weeks later we arranged to meet. For me seeing him in person wouldn’t be too much of a surprise as he was often on webcam walking around. But I was worried for him – I was generally sat at a table with my laptop when he’d seen me, and I was worried that seeing ‘all of me’ would be a disappointment – as still at this point, we hadn’t spoken about my disability.

“We picked a day to meet and as it got closer, I began to get more and more frustrated by the fact that he still hadn’t brought it up! I knew I really liked him and I was miffed at the thought that my disability could spoil everything for me. I was beginning to think he’d missed it on my profile and suddenly panic struck in as I realised that there was no way I could meet him without being sure that he knew. I looked for every opportunity to slip it into conversation but the right moment never came. Eventually on the evening we were due to meet I texted him saying, ‘Look, you do realise I use a wheelchair, right?’ He replied, ‘Yes, of course - why you asking that?’ My reply: ‘I just wanted to be sure.’ His reply: ‘Well it doesn’t matter to me, why would it?’ That was all I needed.

“In my experience, maintaining a good relationship and a ‘normal’ family life with a disability is never an easy thing to balance. Obviously it depends on the severity of the disability, but for me, any privacy and spontaneity I would want in a relationship is pretty much lost when disability is involved. This begins in the early days where taken-for-granted things that happen in ‘the moment’ often become a planned event (at least in my mind, if not literally), and even being intimate with a so-called stranger is awkward and involves a lot of trust from very early on. This lack of privacy and
spontaneity carries on as the relationship gets more ‘serious’ and things like settling down and living together start to happen. In the early days I would never trust or even allow Matt to help me with more personal things, such as going to the loo, but as time went on it became obvious that despite trying to keep a separation between intimacy and care, there are times when he will either have to help me, or that it is just easier for him to help me. Whether either of us like it or not, I need help one way or another.

“One of the most obvious solutions is having a PA’s support, which has its advantages in taking the pressure of caring for a disabled person away from others and enabling a form of privacy. But it also has its many disadvantages. For me trying to maintain both a stable relationship and a functioning family life is extremely difficult when a PA is involved. From the sheer presence of that extra person being around during family time, to the pressure of trying to discipline a young child and get ready for school in the morning with another person around becomes an unnecessary difficult and stressful task, which often takes far longer and subsequently has to begin far earlier than it would for a ‘normal’ family. Trying to organise everyday life whilst at the same time maintaining some form of a schedule with a PA is hard work, and requires planning. This means that that spur-of-the-moment evening together as a couple, whether it be watching TV alone together or going out together, becomes somewhat non-existent. All of these taken-for-granted things come with extra ‘hassle’ that an able-bodied person needn’t even consider. As let’s face it – life doesn’t always go as plain sailing as you might wish for from one day to another.

“All in all I find my disability a huge physical inconvenience at times, but I try my hardest not to let it hold me back. For the most part I see it as a challenge to overcome, but there are times when it does wear me down. Both Matt and I get frustrated, and I find that the pressure is always on me to deal with my ‘baggage’. I find having no privacy hard to deal with, yet I know that needing support means that others will always need to be involved whether I like it or not. Being upset about my inadequacies and feeling insecure about my inferiorities compared with an able-bodied girl obviously occur from time to time, after all I am only human. Having a relationship with a disability is by no means easy, but it is definitely do-able and worth the effort.

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“From the day we met our relationship has grown and moved quickly. There was something about it that just felt ‘right’. I introduced Matt to my son quite early on and he was as accepting as any single mother could ever wish for. As it happens we're now living together, and Holly, our daughter was born in December.”

**Matt:**

“I met Jess on an internet dating site. I saw that she was a pretty girl so looked on her profile. It said that she used a wheelchair but that didn't put me off. I was more concerned about her already having a son to be honest. Anyway it was me that made the first move, sending her a message late one night after reading her profile. She replied quite quickly telling me she was going to sleep but would message me the day after. Anyway a day passed and still no message. I was browsing the site when I saw she was ‘online’ in the chat application. I made sure she was fully aware of the fact she ignored me. Eventually she did reply and we managed to get talking. She will never live down the fact she ignored me and I'll always use that to my advantage!

“After a few weeks of constant texting and phoning we decided to meet up. At this point we hadn't discussed the fact that she was disabled but obviously I knew that she was. I think that the reason that we hadn't discussed it was because it didn't
make a difference to who she was. It wasn't until we had been speaking for well over a month that I found out she actually had muscular dystrophy.

“Since then, we have moved in together and have started to settle down into family life. Until you are part of a disabled person’s life, I don't think you can truly appreciate the extra effort that is required on a day-to-day basis. Whether it's having to avoid certain shops or restaurants, getting in and out of the house or car, cooking food or making a drink, everything requires a lot of effort that able-bodied people take for granted. Sometimes it can get stressful when you want to sit down and relax but can’t because Jess needs help, but there is no way I’d change that. I think the fact that I have to help her in different situations has brought us a lot closer together. When we first got together she wouldn't trust me to help her with the sling to go to the toilet or to get into bed. Now it’s an everyday situation. In my eyes it compares to a couple making a brew for each other or nipping to the shops. It's not a burden because it's for the person I love.

“I admit that it’s not all plain sailing. One thing that can be hard to cope with is Jess having a carer. Living in a two-bedroom flat with a six-year-old child and a carer sleeping over can sometimes get too much. Because Jess's carer stays overnight she sleeps on a 'z' bed in the living room. Because of the nature of Jess’s condition she gets tired a lot earlier than I would normally, so once she's in bed and her carer wants to go to bed it means that I have to get out of the living room. Now a lot of people wouldn't see the problem with being in bed at 10pm - more sleep, less tired. But when you sometimes don't get home from work until 9, the last thing you want to do is to go straight to bed. Plus as we all know humans are creatures of habit, and my whole family normally stay up until gone midnight.

“All in all I would say that the positives outweigh the negatives. If I could change Jess, would I? Not in a million years. Yes, she can grind me down, and yes she sometimes requires attention when I’m not in the mood to give it, but that's not because she is disabled, that's because she is female! If I was to give somebody advice about relationships with a disabled person it would be to be yourself and treat them how you would treat anyone else. Disabled people are no different to ‘us’, just sometimes need a different kind of help than any able-bodied person would.”
One hundred Trailblazers anonymously got involved with this investigation, some had words of advice to give anyone looking for a relationship, friendship or a friendly flirtation!

"Don't give up."

"Get yourself a good circle of friends first so you've got someone to accompany you out socially."

"Go for it and just be yourself!"

"Just go for it, and know that there will be disappointments and let-downs along the way, but never give up. If you really want a relationship you have to keep trying, it takes time and won't happen overnight, whether you have a disability or not."

"Be honest. Trust is the basis of all relationships, romantic or otherwise."

"Talk to people online to build confidence, if you are not a confident person. Get yourself out there."

"It's a scary world, but the only way to make it less scary is to explore it for yourself."

"Just be confident. It may take time but it can happen. And have fun along the way!"

"Be yourself, decide what is important for you in a relationship and see that your needs are met."

"Be yourself. I imagine that's what someone will fall in love with: you as a whole package and not your condition."

"Be confident in yourself and don't let setbacks put you off."

"If you are someone who has never dated, don't be afraid to follow your heart and enjoy the thrill! I have friends who are happily married and starting families who found their other half in unlikely places -- and remember you're as human as everyone else!"

"Trust your inner voice and get a second opinion on character if you are doubtful. Keep safe."

"Tell them about your disability at first and be confident. Don't be embarrassed about your disability."

"Never go out looking for someone. Just be friendly, talk to people and one day you'll realise the person you need is right in front of you!"

"Think carefully about how you would feel most comfortable and most happy in a relationship both generally and in regards to your disability. And then think about whether you personally think that is achievable in a relationship with both able-bodied and disabled people, or with only one or the other? This is purely down to personal
preference, which may be altered by the nature or severity of your disability and the assistance you require. But also down to all other parts of your life and personality.”

“Be FEARLESS and just throw yourself into it. You only have one chance in life to be happy, so do what you love with whom you love.”

Useful links

Muscular Dystrophy Campaign:

www.muscular-dystrophy.org/how_we_help_you/living_with_muscular_dystrophy/sex_and_muscular_dystrophy

www.muscular-dystrophy.org/assets/0002/2958/Relationships_and_sexuality.pdf

Get involved

Take action, campaign, learn skills, make friends. Interested in becoming a Trailblazer? We always welcome people to join our thriving campaigning community.

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e: trailblazers@muscular-dystrophy.org
w: www.muscular-dystrophy.org/trailblazers

Thank you for your support