disability HORIZONS GIVING YOU A VOICE

The Ultimate Disability Survival Guide



Martyn Sibley Co-founder and CEO of Disability Horizons, takes you through The Ultimate Disability Survival Guide

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How to rapidly gain more independence

We show you how to enjoy the social life, passions and lifestyle you've always dreamed of without being limited, left behind or defined by your disability.

One of the biggest reasons why we started <u>Disability Horizons</u> in 2011 was to promote disabled people's independence.

After my nasty visit to hospital in 1999, I vowed to fulfil my dreams. All of them. However, needing help to turn at night, go to the loo, be hoisted, prepare food and drink, open doors (the list goes on), made this tough. Only my parents were doing this back then.

During my time at Coventry University and working/living in London, I found my solutions. You will too.

You see, whatever disability we may have, there are things we're ok doing, and things that are impossible to do on our own. For me, independence isn't about doing everything for myself. It's about having choice and control over my life.

Depending on the barriers resulting from your disability, there are always different solutions. Remember, it'll take time, but you'll get there. Here's how to get your independence...

HEALTH FIRST

One of the aims you should have for your independence is health. In particular, good physical and emotional health.

Physical health comes from plenty of sleep, good nourishment, regular exercise and hygiene. Scientific research is proving this more every year. Personally, I read a lot from James Altucher, Vishen Lakhiani, and Eric Edmeades on this topic. They're not disabled, but health is universal.

Your exercise programme will vary depending on your abilities. It's always good to speak with your professional network of GPs, OTs, physios and such. But here are a couple of links to inspire and get you started:

- Wheely good fitness: fitness customised for wheelchair users

- Top tips for getting fit if you're disabled

Emotional health comes from consuming positive information (I don't read the news anymore), having good family and friends around, and taking setbacks as opportunities to learn. Again, I read a lot from Altucher and Lakhiani on this aspect of health too.

My big message on health to you is that being disabled doesn't justify neglect of any of these. Health always comes first!

CARERS AND PERSONAL ASSISTANTS

Some of us need support to fulfil our needs and ensure we're not neglecting our health.

A carer is really the name of a person who helps without being paid. For years my parents 'cared' for me, and I'm so appreciative of that.

Now, however, I want them to just be my parents. I want my family to be my family. I want my friends to be friends.

So, I get <u>Direct Payments</u> from my Local Authority to pay my Personal Assistants (PAs). Other people have NHS funding. Disabled people who work can use <u>Access to Work</u> funding. This is covered further in the section about money.

Having PAs that I pay for with my Direct Payment means I can recruit, train, and pay my care team. I'm not relying on kindness, nor am I compromising or feeling guilty for my needs.

I go to bed when I want, get up when I want, eat when I want and exercise when I want.

You get my point :-)

Have a think about your disability. Think about the things you can't do, and whether a PA would make a big difference to your independence. If it's a yes, get in touch with your Local Council and request a social care assessment.

Charities, such as <u>Disability Rights UK</u> and <u>Scope</u> can assist you. Plus you should reach out to your local <u>Disabled People's Organisation (DPO)</u> for guidance.

ASSISTIVE TECHNOLOGY

There are a number of things I can do on my own, such as type this guide from my phone, thanks to technology. It opens up a whole new world of possibilities. My PAs even use various pieces of equipment to help support me.

Technology hasn't just revolutionised the world, it's enabled disabled people to do more things independently.

- I have an electric bed to raise my head and legs for comfort at night. Plus, it goes up and down for differing PA heights.

- I have a hoist to lift me between my bed, wheelchair, and bath.
- I have an electric wheelchair with tilt and raise functions.
- I have an adapted car that I drive from my wheelchair.

Beyond disability-specific equipment, I use my phone for reading, writing, work admin, file storage, films and, of course, phoning people :-)

The mobile phone was a lifeline for disabled people needing security when travelling solo or needing care support in the night. In London I would wake my PA to help me turnover by ringing them in the spare room.

Technology offers so many solutions. Checkout <u>Disability Horizons' technology articles</u>, and you'll find many individual solutions to suit your needs.

Plus, <u>Ability Net</u> and <u>iansyst</u> have a wealth of information. Like in this <u>article on workplace</u> <u>adjustments</u>.

HOUSING

I've had so many housing nightmares. University was ok as the halls were adapted for wheelchair users. London was another matter!

I had a new job starting in the October and so I had two months to find my new home. Single, in a low paid job, and with many access needs. It didn't look good.

The usual websites were useless - the people didn't understand accessibility. I viewed 'accessible' places that had steps up to the door. I met a drug dealer renting out his social housings spare room. It seemed to get bleaker by the minute.

In the end, a beautiful two bed flat became available for part rent and part buy. With some tweaks to get my manual hoist over the bath, I did it!

Here's a list of helpful resources:

- Visit the <u>Ability Housing website</u> here.
- Visit the <u>Home Match website</u> here.
- Search for properties on <u>Habinteg's website</u> here.
- Visit the Accessible Property Register website here.
- Visit <u>TheHouseShop.com website</u> here.

- Visit the <u>Branch Properties website</u> here.
- Download the <u>DH Housing Guide</u> here.

So, aim high, know it'll be tough, don't give up, and trust that it'll all work out. It always does!

TRANSPORT

I mentioned my adapted car. If that sounds cool, please contact <u>Motability</u> for an assessment. They'll ask you relevant questions and test your abilities at their driving centres. Then they'll recommend how you can best drive independently.

Equally, driving might not be for you. I've used buses, taxis, trains, and planes, all to greater and lesser successes. Here's a great article from Disability Horizons <u>on getting</u> <u>around London</u>.

TRANSPORT TIPS

Do your research - with the internet you can find out accessibility and other general journey information, such as times and distances.

Ask friends or the <u>DHorizons Tribe Facebook group</u> for tips - if you're going somewhere for the first time, use the experience and insights of your peers.

Leave extra time for hold-ups - something will generally go a bit wrong. If you have a buffer of time it then doesn't have to ruin your day.

Keep moving forward in life and stay optimistic - complaints do lead to improvements, but stress and anxiety don't. So always try to stay positive.

Also remember, self-driving cars aren't far away ;-)

HOW TO GET THERE

Once you have good health, care support, assistive technology, transport, and housing, you can really excel in life.

We'll cover money in another section. It is related to independence, but as the costs of being disabled can be high, it needs it's own section to help you be financially independent.

Once you're independent, the world becomes your oyster :-)

From my initial experiences as a disabled kid, I have gone on to live my life to the fullest. I have made many amazing friends, enjoyed romantic experiences (see the sex and

relationships section), watched my beloved Tottenham team play football, attended music festivals, travelled to many countries, lived in Spain, <u>written a book</u>, and started multiple businesses.

My adventurous streak went so far that I flew a plane, went skiing in Catalonia, SCUBA dived in <u>Tenerife</u>, husky dog sled in <u>Finland</u> and much more. This all landed me on TV, corporate stages, and winning awards.

Please dream big! Get independent and enjoy the ride...

HERE'S A HELPING HAND ...

If you're struggling to live independently, do not have the right support, and are feeling generally lost, try this.

List 5 things that would help you. Use it as a way to record what you need and as an expressive tool. Let it all flow out. How would you benefit from the assistance? Might tech help? What do you need to get there? Who could you speak to about it?

Then write down the 1 most urgent question you have from it all. If you haven't already, join our exclusive <u>DHorizons Tribe Facebook group</u>, post the question, and we can help find the solution.

How to become financially independent

We show you how to make more money and access all the help you're entitled to without being limited, left behind or defined by your disability.

Money, money, money.

The root of all evil? Grows on trees? Borrow from Peter to pay Paul?

We've all aspired to have money. Maybe not for crazy wealth, but for housing, food, leisure and transport at least. Although I am sure many have also dreamt of extreme wealth!

It gives us freedom. It gives us time. It gives us safety.

In its absence, it also causes stress. It can result in relationship failure. It can have very bad consequences.

For us disabled people, it can mean no care support, no assistive technology, no housing and no transport. Let alone any life or fun!

So here's how to get you what you need...

GOVERNMENT SUPPORT

The rights of disabled people in the past 100 years have increased vastly. But, in more recent times, since the financial crisis, austerity has hit us hard. We've seen a regression in some areas.

For those in need of support who have had it taken away, please know that the Disability Horizons' community is here for you. Even if to just vent or to be sad, or to ask questions, our <u>DHorizons Tribe Facebook group</u> is here for you.

Nonetheless, there are laws and policies in place that should enable you to get what you need. So if you qualify for support, sometimes it's just about understanding the tick boxes, and making sure you communicate your needs within these parameters.

Every year I have to 'prove' my disability. I have to repeat all the things I can't do, and it sucks. But without my independence, I'm screwed. So I schedule these things in, do

what I need to and move on. When necessary, I fight - hard.

I have <u>Personal Independence Payment</u> (PIP), for the extra costs of living with a disability. I have social care Direct Payments for employing my PAs. I have the <u>NHS</u> voucher for my wheelchair. Plus grants for other assistive technology.

Every form and assessment will vary, as does each disability. All I can suggest is make sure you highlight your worse day. It's all too common for people talk about a good day, and are left struggling on an average or bad day. Maybe it's because we try to keep positive and optimistic. In these moments I give you permission to be very pessimistic. I do not mean lie about your needs, but instead be very truthful and don't ignore your real needs.

There are many websites and charities out there who can help with financial matters too. <u>Disability Rights UK</u>, <u>Scope</u> and your <u>Local Disabled People's Organisations</u> (DPOs) are good places to start.

Also, you can Google any questions you have (e.g. how can I apply for PIP?). And, of course, our <u>DHorizons Tribe Facebook group</u> can help you out. Just share your questions and concerns in our Facebook group.

Just remember, you didn't choose to be disabled. A government should support those in need, in part because it could happen to anyone any day. Be confident and don't feel guilty about using government funding.

WORKING HARD OR HARDLY WORKING

Unfortunately, disabled people sometimes get a bad name in the media. We're either heroes for leaving the house, or benefit scroungers because one person scammed the benefits system and the Daily Mail wrote about it like it happens everywhere.

I believe that disabled people want to work. Those who simply can't work must have financial help. For the rest, one issue is a lack of independent living support. Another is inaccessible transport and buildings. Another is employer discrimination.

Behold the internet!

It's now not only possible for disabled people to work from home, but most people are doing it, disabled or not!

Gone are the dark days of having to get into an office. Just pick your passion, learn a skill, apply for jobs or start that company! You truly can now earn more money with a disability. I see it everyday on our social media posts :-)

Naturally, if you want to work in a place of employment, that's absolutely possible too. I had six great years working in a London office with 200 people!

Don't forget to check out our <u>employment zone on Disability Horizons</u>. There are many articles on disabled entrepreneurs and employees. All doing great stuff.

Remember, care and equipment will be funded by the government. But you'll be proud to pay your own bills, enjoy the best food, and treat others to presents. Plus, there's nothing like contributing your unique talents for the rest of the world to enjoy.

This might seem far away for some of you. Just use unemployment support, start making progress, and it'll fall into place bit by bit.

SAVINGS AND INVESTMENTS

A final thought. Once you're earning, please do me a favour - save and invest a percentage. Of course, cover the basics and have a holiday. But save and invest too.

I hope to one day work purely for the love of it. My job is the best job ever. But to get financial freedom, my investments need to pay for my MLI (Minimum Liveable Income).

We've all gotta dream right!?

This takes us back to the beginning and those questions about money being evil or growing on trees. I think that if you see money as a neutral man-made tool, you'll be less stressed and more-free. It's absolutely vital for living, but it's also just paper, metal, or numbers on a computer screen.

Abundance is a lifestyle choice. It doesn't replace hard work and clever decision making. You can do those things anyway. It simply is a way of seeing the world. A world where everyone has what they need and more. There's plenty to go around for everyone.

To explain this point better I recommend you read <u>Abundance by Peter Diamandis</u>. It took me a while to grasp this world view. So just be open to the sentiments that money is a tool. There's plenty out there. You just have to find your value in the game of life to earn it.

HERE'S A HELPING HAND...

List all of your beliefs about money and your chances of earning well. Question where these beliefs came from. Are they true? Are they working out well for you?

Also, what is your personal MLI (Minimum Liveable Income)? Calculate your accommodation, food, clothes, transport, leisure and anything else absolutely vital. Once you know your MLI, it makes it easier to plan for how to achieve, then surpass it.

Naturally, there are real barriers to working. What are they for you? How can they be solved? Share your most pertinent questions and problems with the <u>DHorizons Tribe</u> <u>Facebook group</u>. They'll listen and offer solutions.

'Rome wasn't built in a day'. You're doing great wherever you are today. Celebrate your successes, appreciate what you have, but also dream big. Know that you deserve everything and go get it.

It's just the game of life :-)

How to have amazing, bedshaking sex and wonderful relationships

We show you how to have fulfilling relationships and sex without being limited, left behind or defined by your disability.

Boom shake the room!

I seem to remember playing that 90s song for an old girlfriend. Cringe!

Dating and relationships have always meant a lot to me. Maybe because I feared my disability would stop this part of my life. From a young age, I was worried no one could see themselves with a disabled guy.

But, gradually I got the confidence and self-esteem to believe I could find love. Just like anyone else. Then the rest followed :-)

TOP TIPS FOR RELATIONSHIPS

For me, the following areas are key to making your sex and relationships awesome:

- Understand yourself and what you want I'd suggest writing a personal statement about the type of person you are, as well as the type of person you want to be with, and what your ideal relationship looks like.
- **Start your search** expand your search for love far and wide. Go online eg. social media and <u>dating sites</u> and offline eg. social/sports clubs.
- **Create a plan** think about the etiquette you'd use once you've got a date and what you want to tell them about your disability. Do what's comfortable for you, but remember, you shouldn't be ashamed because you might need to do things a little differently.
- **Plan your first dates** think about appropriate activities, transport and care for you. Make sure you own it. Never feel silly for having your needs covered.
- **Getting intimate** once the moment is right, how will you progress the relationship? Are there any physical limitations and, more importantly, what are the ways around them?
- Balancing your relationship and needs think about how to keep the spark and be independent. There are many challenges to being in a steady relationship. If you're disabled, one is balancing your relationship with your personal care needs.

SEXY TIMES

I'm very British when it comes to sharing sexual experiences. Well, I did write a warts and all (not the best synonym to use, I know) blog post years ago, which got me in trouble with a couple of ex lovers :-)

All I'll say on a personal level is that despite having very little physical strength, I've had lots of amazing sex. I believe it comes down to having strong self confidence, real human connections, and an adventurous streak. I've certainly managed more positions (and girlfriends) than I thought possible.

To get you started, here are two of our most popular Disability Horizons relationship articles, both on sex toys. They show that you always get your rocks off solo, or indeed use the toys with company.

- Disability and Sex: the ultimate guide to sex toys
- Disability and Sex: let's be frank about sex toys

LONG-TERM LOVE

Picking up more from the last point in the first section, I want to impress the importance of balance. With any romantic relationship, the difficulty of how much care you have comes into play as you won't want your PA present during a romantic dinner or foreplay. Being able to just be with your partner alone is amazing. However, having a partner struggling with being your sole carer, or you sacrificing independence for your partner, is bad. You must have independence for both of your sakes, so striking the right balance is crucial. My advice is to be self-aware, compassionate, communicative, innovative and sometimes compromising. They never said love was easy! But it's all totally possible :-)

Disabled or not, this stuff is tricky. So don't beat yourself up or be too serious. Buy those sexy clothes or nice smellies. Be confident in who you are, and laugh at life's challenges.

The 'one' always pops up. It took me horrible heartache, long single spells of despair, and me being the wrongdoer, before I found my soul mate.

As always, the <u>DHorizons Tribe Facebook group</u> is waiting to hear about your challenges and for you to share your ideas :-)

We have loads of saucy information on our <u>Disability Horizons sex and relationships zone</u>. Please check this out too.

We are looking forward to hearing your questions, getting you those answers, and ultimately you finding your soul mate...

