

The lived experience of impaired mobilityPETER¹

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LIVING WITH ADAPTATION

Peter, now 50 years old, has been a mobile, active, and fairly healthy man throughout his life; enjoying the gym, running and a range of outdoor pursuits including walking and beach fishing, as he lives near the coast. Just over a year ago, when Peter was on his way to work, he had a motorcycle accident that led to the amputation of his left leg through his knee.

After his amputation, he sees himself as continuing to remain fairly fit. He can walk a couple of miles and he continues with beach fishing, maintains his fitness with an adapted gym work out and drives an automatic car. He has not been able to return to riding his motorbike, which he does miss.

Peter's career had been in retail management, but immediately prior to his accident he had changed jobs. The change in jobs unfortunately meant he was unable to qualify for sick pay and he was forced to resign soon after his accident. Now Peter is concerned about his prospects for employment.

ADJUSTING TO ALTERED MOBILITY

Adjusting to living with his altered mobility has been a steep learning experience:

'One of the most disconcerting things I found was that I couldn't stand up on one leg, which of course you can always do beforehand, so it comes across as completely... I just used to collapse, which I now know is quite common, and just all sense of balance had just gone.'

The common experience that interferes with Peter leading his life in an unplanned and in a reactive way, as he used to, is the lack of spontaneity:

'Yes, there's no spontaneity there, it's all... I've got to think about what I'm doing all the time, otherwise I can fall over.'

Peter tells of how tiring moving about can be; bending is particularly challenging for him and he describes this as being '*extremely tiring*' (emphasis in conversation). Even for someone as fit as him it can be a difficult manoeuvre to get up from sofas, get in and out of cars and use toilets. Until he has a walk-in shower with a seat and hand holds to limit this risk of falling, Peter has decided to forgo using the shower. Limitations outside arise from wet or windy weather which might limit his outdoor activities as it becomes slippery underfoot. When he is out walking, Peter assesses the

ground for hazards to reduce the risk of falling. The lack of sensory feedback from the artificial limb is problematic. He dislikes going out in places that are crowded when he cannot see the floor, as he can tread on people without knowing, and similarly people can tread on him without his knowing:

'I've had it where I've gone to walk off and I've just fell over because somebody was stood on my foot, and of course I didn't know.'

As Peter recounts his new life with an artificial limb, we hear about the various physical problems that he encounters, including: having knees of differing heights; difficulty in taking stairs; the challenge in putting pressure on the front of his foot, leaving him prone to slipping; the inability to run; and the limitations of his prostheses in getting down to sit on the floor.

FAMILY LIFE

Peter is a dad to three children who are 16 and 12 years old and the youngest, a four-year-old. Unfortunately, floor play with her is not enjoyable for Peter. His artificial leg is not controlled, the limb is hard to manoeuvre and it is possible that his leg can kick out. The lack of spontaneity in playing with young daughter causes some sadness for Peter and he reflects that he misses not being able to run around with her.

INTIMACY

Peter draws our attention to the impact that the amputation might have on intimacy:

'I don't know if anybody else has touched on this by the way, but purely another aspect that it severely limits is your sex life.'

Following his amputation Peter's knees are at different heights, so kneeling is very difficult for him. Peter highlighted how spontaneity is so adversely affected, giving an example of moving from the floor to the bed. Peter would need to remove his leg since or else he felt it would be:

'...probably dangerous and mean sort of kicking someone or hurting them quite badly. So, things like that, once again because I have no control over the lower part of the leg, so it doesn't sort of do what I want it to do.'

LEISURE

Beach casting (fishing) has always been a part Peter's social life. He feels 'severely limited' in his ability to continue this pursuit due to the inaccessibility of the beach and the concern that he may get sand and salt water into the hydraulics of his prostheses. The rocky terrain is tricky for walking and he needs to assess the environment and know where he is walking; this is made harder by not

being able to exert enough force through his prosthetic foot to walk across this type of terrain. He tells us that he cannot effectively use the front half of his prosthetic foot because he has no ability to move the foot, so any force is just transferred through the heel:

'...So, if you put your foot down with this one (points to right foot) you get a nice footprint but if I put my foot down with that one (points to artificial limb), I don't, because the weight all goes down through there pretty much, so it's only that bit that goes on. So, you just don't have the grip, and you've got to be very careful.... Like I say, if you could see the footprints that I can put down you would understand immediately, and it really is so noticeable that I cannot put any kind of pressure on the front part of my foot, and so I'm very prone to slipping, which does explain why I do slip around so much.'

Whilst there are ways around this, it is again, a trade off; in order to achieve even 15%-20% of the amount of beach casting that he used to do, he must be prepared to hose his limb down afterward to wash out the sand.

SPORTS

Peter continues with his gym sessions, but he has been forced to adapt his routine, due to the limited amount of weight the prostheses can bear:

'I still go to the gym now every two or three times a week, but I've had to... It's one of the downsides, I've seriously had to adapt what I do, because a lot of exercises are basically either squatting or lifting weights from the floor, etc., and it's not something I do particularly well. And, also I could break my leg which would then cause me problems, because the weight limit on them is not particularly great, it's about 120 kilos, and I weigh 85/90 kilos, so..'

THE SOCKET AND THE STUMP

The surgery left Peter with a long stump which he advises us is better for socket fit. The stump and the socket can begin as a good fit but then become, what Peter calls, '*less good*', which has led to unsafe experiences. For instance, he had an incident at the gym when trying to complete a pull up and, as the quality of the fit had degraded, his leg came out of the socket. In another incident, on the rowing machine, his leg came away mid exercise.

The stump can be uncomfortable and when he exerts himself this can lead to a breakdown in his skin. The stump frequently changes shape as it swells and shrinks when it heats and cools. Another issue is water getting into the socket which then leads to pain; on such a day, he would use the wheelchair as it would be easier to move around. When mobilising, Peter's leg settles back in the

socket leading to an audible expulsion noise and this aspect interrupts his conversation as he apologises for the noise and explains its cause.

THE LIMB

While he has found adjusting to walking with an artificial limb relatively easy albeit tiring, Peter has identified the limitations of the legs and how they impact upon not only on walking, but how he can plan to spend time in a day. His usual prosthetic leg he regards as a nice leg with a very good stumble recovery, but the downside is that it is *'much more physically demanding'* to use and it tires him more swiftly. He has an alternative prosthetic leg which he finds very easy to use, and he says he can whizz along as it is significantly lighter. However, the stumble recovery on his alternative prosthetic is poor and he has experienced *'flying flat on my face into things'*. This had led Peter to favour the heavier limb with better stumble recovery.

The issues of weight and ease of use require Peter to make decisions about his use of time and the trade-off required. Peter would like to shop in a large mall, and he knows that he will need to rest at some point. However, for Peter, the exertion required will mean that the following day he will be too tired to have an active day.

OTHER DEVICES

When Peter goes out, he is comfortable using a wooden walking stick which he describes as *'a big player in my everyday life,'* as using this makes it easier to get up should he fall. He also has crutches and a wheelchair, as alternatives in the event his artificial limbs or his stump should fail.

To support his daily living, he has handrails in the bathroom: a handrail above a seat across the bath; one on the wall; and two by the toilet. However, when not at home using bathrooms and toilets can be difficult, even with use of his stick to offer support.

PRESENTATION OF THE ARTIFICIAL LIMB

Seeing an artificial limb on show is not as unusual as it might once have been and Peter is happy for people to see his leg:

'People are nice to you when they see the leg as well, it's one of those things'

He feels that it stops people thinking he is drunk and from a practical viewpoint, he finds it more comfortable and limits the chances that his trousers may rip or get caught. Initially disliking his prosthetic limb as a totem to what he had lost, Peter now quite likes it and calls the technical parts that are displayed *'leg jewellery'*.

WHAT PETER WOULD LIKE TO BE ABLE TO ACHIEVE

'One of the things I would like more than anything else in this world is to be able to walk upstairs normally. Or more confidently, I think, from my point of view would actually be... just to have that feeling of... Have it feeling less like a dead leg, if you like.'

He would like to be able to walk quicker and have a better grip under the foot of the prosthesis to reduce the slipping. Peter is very supportive of the idea of new soft adaptive technology to solve the limitations of his prostheses. He felt that carrying a battery for power of some 5-6 kilos would be an acceptable trade-off for increased walking performance, either increased speed and/or increased range. The new wearable devices need to be comfortable and be easy to get on and off.

WHAT IS THE POTENTIAL FOR THE NEW GARMENTS

Peter felt that homebound, frailer and more elderly people might benefit more from the new devices than someone like himself, as the garments would offer them freedom to get out of the house: *'..some kind of wearable tech could genuinely be an absolute godsend to some people...'*

WHAT WE HAVE LEARNT FROM PETER

Peter's story emphasises the need for the garments to truly offer an advantage that cannot be gained from existing devices. In order to optimise this gain, devices should be easy to get on and take off and provide a form of fast feedback to facilitate foot placement:

'You need to have something that offers some ray of hope of improving or offering something completely different to what they can currently achieve.'