

theguardian

# NEUROPHILOSOPHY

## MO COSTANDI

HOSTED BY THE GUARDIAN



## The science and ethics of voluntary amputation

Should amputation be offered as a treatment to people suffering from Body Integrity Identity Disorder?



In Habib Azar's 2010 black comedy *Armlless*, Daniel London plays John, who has a compulsive desire to have both of his arms cut off

Earlier this month I gave [a talk](#) about a condition called *Body Identity Integrity Disorder*, which is characterised by the desire to amputate a healthy limb. I described the possible neurological basis of the condition, and then argued that surgical amputation should be offered to those sufferers who request it. Here's a summary of the talk.

In January 2000, the mass media ran several stories about [Robert Smith](#), a surgeon at the Falkirk and District Royal Infirmary who had [amputated](#) the legs of two patients at their own request and was planning a third amputation. The news stories incorrectly described the patients as suffering from Body Dysmorphic Disorder. They further stated that the director of NHS trust running the hospital at which Smith works described the amputation of healthy limbs as "inappropriate"; since then, no British hospital has performed a voluntary amputation.

The patients were, in fact, suffering from Body Integrity Identity Disorder (BIID), an apparently rare condition characterized by a burning and incessant desire to amputate an otherwise perfectly healthy limb. The first documented case of BIID dates back to a medical textbook published in 1785, by the French surgeon and anatomist Jean-Joseph Sue, who described the case of an Englishman who fell in love with a one-legged woman, and wanted to become an amputee himself so that he could win her heart. He offered a surgeon 100 guineas to amputate his leg and, when the surgeon refused, forced him to perform the operation at gunpoint.

Subsequently, the pioneering neuropsychiatrist Richard von Krafft-Ebing described

three cases of what appear to be BIID in his classic 1906 book, *Psycopathia Sexualis*. "Even bodily defects become fetishes," wrote von Krafft-Ebing. He describes a 28-year-old factory engineer, who "complained of a peculiar mania, which caused him to doubt his sanity." He continues:

Since his 17th year he became sexually excited at the sight of physical defects in women, especially lameness and disfigured feet. Normal women had no attraction for him. If a woman, however, was afflicted with lameness or with contorted or disfigured feet, she exercised a powerful sensual influence over him, no matter whether she was otherwise pretty or ugly. In his dreams... the forms of halting women were ever before him. At times he could not resist the temptation to imitate their gait, which caused vehement orgasm with lustful ejaculation... He thought it would cause him intense pleasure to mate with a lame woman. At any rate, he could never marry any other than a lame woman.

This is followed by a second case:

He used to limp about the room on two brooms in lieu of crutches, or when unobserved, go limping about the streets... in his erotic dreams, the idea of the limping girl was always the controlling element. The personality of the halting girl was a matter of indifference, his interest being solely centered in the limping foot. He never had coitus with a girl thus afflicted. His perverse fancies revolved around masturbation against the foot of a halting female. At times he anchored his hope on the thought that he might succeed in winning and marrying a chaste lame girl... His present existence was one of untold misery.

Finally, Krafft-Ebing describes the case of a 30-year-old civil servant:

...since his 7th year he had for a playmate a lame girl of the same age. At the age of 12, puberty set in, and it lies beyond doubt that the first sexual emotions towards the other sex were coincident with the sight of the lame girl. For ever after only halting women excited him sexually. His fetish was a pretty lady who, like the companion of his childhood, limped with the left foot. He sought early relations with the opposite sex but was absolutely impotent with women who were not lame. Virility and gratification were most strongly elicited if the woman limped with the left foot, but he was also successful if the lameness was in the right foot. His sexual anomaly rendered him very unhappy and he was often near committing suicide.

The first modern case studies of BIID were published in the *Journal of Sex Research* by John Money. Money referred to the condition as apotemnophilia, meaning, literally "amputation love," and distinguished it from acrotomophilia, or a sexual attraction to amputees. The suffix "philia" denotes that BIID is a paraphilia, or what is commonly called a perversion. To this day, few psychiatrists know of the condition; and most of those that do know consider it as a fetish in which the stump of the amputated limb is fetishized because it resembles a phallus.

Most BIID sufferers, however, describe their feelings in terms of identity, instead. "My left foot is not a part of me," said one of Smith's patients. "It feels right," says another sufferer, "the way I should always have been and for some reason in line with what I think my body ought to have been like." "I didn't understand why," says yet another, "but I knew I didn't want my leg."

So while there can be a sexual component to the condition, most BIID sufferers do not give sexual motives for wanting an amputation. This led Michael First, a psychiatrist at Columbia University in New York, to rename the condition. He initially considered

calling it "amputee identity disorder," but then settled with BIID.

To date, there have been approximately 300 documented cases of BIID. Most of these are male, almost all of whom desire amputation of a limb on the left side of the body. More often, it is the arm that is affected rather than the leg. All of these so-called "wannabe amputees" know exactly where they want the limb to be cut off, to the millimetre, and almost all of them remember seeing an amputee at a very young age and thinking that they should have been born like that themselves. "When I was 3yrs old, I met a young man who was completely missing all four of his fingers on his right hand," said one 21-yr-old female BIID sufferer, "and ever since that time I have been fascinated by all amputees, especially women amputees who were missing parts of their arms and wore hook prostheses."

Most wannabes also pretend to be an amputee prior to having the limb removed, by tying the limb back, or using a wheelchair or crutches to move around the house. This behaviour could be analogous to cross-dressing in transgender individuals before they undergo sex reassignment surgery. But just as some transgender people are content cross-dressing regularly without going through hormone treatment and surgery, so too are some wannabe amputees are content pretending.

This suggests that BIID occurs with varying severity, with the mild form manifesting itself as an attraction to amputees, and more severe forms manifesting as a desire to amputate. There is overlap between the two, with some wannabes also being attracted to amputees. And if people who are attracted to amputees (or "devotees") are also considered as suffering from BIID, then the condition may not be so rare.

BIID came into the public eye in the early 1970s, with the publication of a series of readers' letters in *Penthouse*. The letters were sent in response to an initial letter from a one-legged woman describing men who were attracted to her, and became so popular that they led to a regular column called *Monopede Mania*.

It's not just limbs that are affected, however. Some BIID sufferers desire having their spinal cord severed; others feel strongly that they should have been born with multiple sclerosis or some other affliction. In *Psycopathia Sexualis*, Krafft-Ebing notes that the French philosopher Rene Descartes was attracted to cross-eyed women – and may, therefore, have suffered from a mild form of the condition.

BIID can be thought of as a body image disorder. The body image concept dates back about one hundred years, to the work of the neurologist Henry Head, who studied many patients with damage to the parietal lobe of the brain. Head found that these patients had profound disturbances of bodily awareness, and postulated that this region of the brain encodes what he called the *body schema*, a postural model of the body. Subsequently, the pioneering neuropsychiatrist Paul Schilder built on this and coined the term *body image*.

We now know that the brain encodes multiple neural representations of the body, some of which are static, and others dynamic. These representations manifest themselves as a mental picture of the body, its form and movements. The brain generates these representations by integrating touch, proprioceptive, and visual information, and this occurs in a region called the right superior parietal lobule.

It is currently thought that BIID occurs because the affected limb is not represented in the body image, so that sufferers have no sense of ownership over it. Early evidence for this idea comes from [Vilayanur S. Ramachandran's](#) lab at the University of California, San Diego. In a very simple experiment, Ramachandran and his colleagues recruited a small number of BIID sufferers seeking leg amputation, and then prodded the affected limb while recording their brain activity using a technique called magnetoencephalography.

The study showed that the touch elicited a response in the primary somatosensory cortex, where sensory information from the leg is initially processed, but not in the superior parietal lobule, where the information would normally be integrated with the other types of sensory information to generate the body image. These findings suggest that BIID occurs as a result of a discrepancy between the body image and the physical form of the body, which would create cognitive dissonance, or contradictory thoughts and feelings.

The idea of amputating healthy limbs is anathema to most surgeons, but I would argue that in some cases it might be the best possible treatment option. My rationale is simple. Psychotherapy and drugs are completely ineffective in alleviating the condition, and BIID sufferers will go to any length to be rid of the unwanted limb. Some build home-made guillotines, blast their unwanted limbs off with a shotgun, or try lie under a jacked-up car and try to crush it. One particularly popular method is to submerge the limb in dry ice for several hours, in order to damage the limb irreparably and thus force doctors to amputate. In May 1998, a 79-year-old man from New York travelled to Mexico for a black-market leg amputation, and then died of gangrene in a motel about a week later.

Offering a clean surgical amputation to those BIID sufferers who really want it would therefore minimize the harm that they might cause to themselves by taking matters into their own hands.

[Previous](#)

[Blog home](#)

## **Ads by Google**

### Hands-On Solar Training

Solar Training Courses 5 Day Design & Installation Class

[CleanEdison.com/Solar](http://CleanEdison.com/Solar)

### Columbia Coupons

1 ridiculously huge coupon a day. It's like doing Columbia @ 90% off!

[www.Groupon.com/Columbia](http://www.Groupon.com/Columbia)

### Private banks Switzerland

Open an account at private banks Switzerland

[www.alpenrosewealth.com](http://www.alpenrosewealth.com)

## **Comments**

75 comments, displaying  first

 Staff

 Contributor



**danielmbarros**

30 May 2012 6:48PM

Either we permit this kind of surgery or forbid the sex-change operation, for it is the same psychopathological phenomena.

[Recommend?](#) (8)

[Responses](#) (2)

[Report](#)

[Link](#)



**Sssssssssssss**

30 May 2012 7:10PM

"When I was 3yrs old, I met a young man who was completely missing all four of his fingers on his right hand," said one 21-yr-old female BIID sufferer, "and ever since that time I have been fascinated by all

[Recommend?](#) (3)

[Responses](#) (2)

[Report](#)

[Link](#)

amputees, especially women amputees who were missing parts of their arms and wore hook prostheses."

Doesn't that clearly say, that there is just a strong empathy for disabled people? Also a fascination by strange things (which is absolutely normal, all newspapers live from the interest for strange things) So, leading to the wish to be like them?

Also, maybe they also want to be something special. If people cannot draw the attention of other people to them by good deeds, they sometimes try it by negative deeds. (extreme sports, doing something for a dare, arson, even murder, - that's often attention-seeking)

May I mention, that obese people also often think, that all their problems will be solved, if they only lost weight. Which is not the case, and so they start eating again.

Can be these BIID people are thinking, that all their problems will be solved if they only lost that limb? Maybe that limb is a symbol for their other everyday problems? Get rid of the limb - get rid of your problems.

Would be interesting how they feel after that amputation and how they are doing then. Also many years thereafter. Do they get a certificate of disability if they give away a leg? (including all the social benefits for disabled people?)

And isn't that some sort of cosmetic surgery, like getting big tits? People don't like their body and so they want to get it changed. In case of cosmetic surgery we often see, that people want more and more of such surgeries. How are the BiIDs doing in this regard?

I hope they have realized after the first surgery, that that was a stupid idea.



**Sssssssssssss**

30 May 2012 7:23PM

Response to [danielmbarros, 30 May 2012 6:48PM](#)

Maybe some people are suffering from the "I can change the world"- craze.

They want to change their genitals, their limbs, their haircolour, their spouse, the government, the climate, .....

Can't they accept the things as they are?

I am sure only humans are that change-manic.

[Recommend?](#) (1)

[Responses](#) (1)

[Report](#)

[Link](#)



**Maybug**

30 May 2012 8:48PM

Fascinating. Has any work ever been done on whether the sexual features of their bodies that trans people don't identify with don't map to their body image? Would there be any way of finding out

[Recommend?](#) (5)

[Responses](#) (1)

[Report](#)

[Link](#)

whether they map to the body image of the physical sex they identify with?



**MacRandall**

30 May 2012 9:37PM

This comment was removed by a moderator because it didn't abide by our [community standards](#). Replies may also be deleted. For more detail see [our FAQs](#).



**Sssssssssssss**

30 May 2012 10:39PM

Response to [Maybug](#), 30 May 2012 8:48PM

Do you mean, they should rather ask for a new brain instead of new genitals?

BTW, limb-cutting also looks like some sort of suicide. Like suicide in miniature, partly, so to speak.

[Recommend?](#) (1)

[Responses](#) (0)

[Report](#)

[Link](#)



**Expecten**

31 May 2012 12:14AM

Response to [Sssssssssssss](#), 30 May 2012 7:23PM

Maybe some people are suffering from the "I can change the world"- craze.

Craze? We do change the world - each and everyone of us.

[Recommend?](#) (0)

[Responses](#) (1)

[Report](#)

[Link](#)



**Sssssssssssss**

31 May 2012 1:43AM

Response to [Expecten](#), 31 May 2012 12:14AM

yes, but some people want to change it a little more than necessary.

[Recommend?](#) (1)

[Responses](#) (0)

[Report](#)

[Link](#)



**Neuron26**

31 May 2012 3:36AM

This article does a good job of providing a context for possibly understanding apotemnophilia -- except for its excursion into the theory provided by V.S. Ramachandran. Unfortunately, Ramachandran's theory is nothing more than an intellectual sleigh of hand. He claims that the desire for the amputation of a limb is created by a mismatch between sensory information arriving in the somatosensory cortex and the body image map that exists in the parietal lobule. This theory would have made sense in 1970. However, modern neuroscience abandoned the notion of a localized body image map 25 years ago. This is another example of Ramachandran providing an explanation that looks like science but which is, in fact, science fiction that is twenty five years out of date.

[Recommend?](#) (5)

[Responses](#) (2)

[Report](#)

[Link](#)



**willothewhip**

31 May 2012 10:07AM

Hello Mo,

Have you considered the influence of Neuroplasticity on this condition ?

i.e if someone spends day after day, year after year thinking about, desiring and imagining amputee-ism, isn't it possible this can rewire their brain and deceive them into thinking they're supposed to be one ?

Or to coin a phrase "You become like the company you keep" !

[Recommend?](#) (6)

[Responses](#) (1)

[Report](#)

[Link](#)



**MWheeler**

31 May 2012 2:27PM

Response to [danielmbarros, 30 May 2012 6:48PM](#)

Yes, there is a noted parallel between GID and BIID. It is an identity disorder.

[Recommend?](#) (0)

[Responses](#) (1)

[Report](#)

[Link](#)



**MWheeler**

31 May 2012 2:32PM

Response to [Ssssssssssss, 30 May 2012 7:10PM](#)

It isn't about getting attention at all. Those who have managed to get elective amputations have found a peace with themselves, that their psychological bodies are in accord with their physical bodies. I would prefer to be a paraplegic locked within a house with no escape than to be out in public in a wheelchair where everyone took notice of me. It's about personal harmony with a mis-matched body, not "Hey- look at me- I'm a cripple!"

[Recommend?](#) (1)

[Responses](#) (0)

[Report](#)

[Link](#)



**MWheeler**

31 May 2012 2:41PM

Response to [Neuron26, 31 May 2012 3:36AM](#)

First- apotemnophilia **IS NOT** BIID!

Most of Ramachandran's work dealt with the phantom limb phenomena experienced with amputees, BIID was a side-track (to my understanding). I don't see where the abandonment of the body map occurred- can you give a reference for this? The concept of the homunculus is pretty well established, and there are clear links in the parietal lobe dealing with body image. These are established facts, it is suspected that this is where the defect lies.

[Recommend?](#) (1)

[Responses](#) (1)

[Report](#)

[Link](#)



**jojosar**

31 May 2012 2:45PM

Response to [MWheeler, 31 May 2012 2:27PM](#)

Yes, but unlike GID there is no treatment available, sufferers therefore feel their life is either one of suffering or self harm,

[Recommend?](#) (0)

[Responses](#) (1)

[Report](#)

[Link](#)

with shame and social isolation thrown in for good measure.  
Does anyone know of any UK based support groups for BIID?



**MWheeler**

31 May 2012 2:52PM

Response to [willothewhip](#), 31 May 2012 10:07AM

I've wondered about neuroplasticity with regard to my own BIID and whether it was a possible cause. It just didn't seem to fit. I knew that my body was somehow wrong at the age of 6 years (most of us will tell you that the onset is in early childhood), I didn't need to talk myself into it. At this age I wasn't obsessed with pretending or assuming a disability- I just knew there was a mismatch that I couldn't identify- until I saw an amputee for the first time. The association was immediate.

[Recommend?](#) (2)

[Responses](#) (0)

[Report](#)

[Link](#)



**MWheeler**

31 May 2012 2:55PM

Response to [jojosar](#), 31 May 2012 2:45PM

biid-info.org, transabled.org, the "fighting-it" yahoo group. Sadly, no support groups to meet face to face. I'm in the southeastern US. BTW: your empathy is greatly appreciated!

[Recommend?](#) (0)

[Responses](#) (0)

[Report](#)

[Link](#)



**rigels**

31 May 2012 3:16PM

This comment was removed by a moderator because it didn't abide by our [community standards](#). Replies may also be deleted. For more detail see [our FAQs](#).



**MWheeler**

31 May 2012 3:39PM

Confused article, mixes BIID with too many other things- not focused very well.

Thanks for recognizing that BIID goes beyond amputation alone- the author is one of the few to recognize that, even if only briefly stated.

The last paragraph. Thanks for that! Some of us do get desperate and take matters into our own hands, the result is either a guaranteed failure or a result far worse than intended.

Psychiatric help does nothing, pharmacotherapy is a dead end. Those who have managed to get their surgeries are the only ones to find relief.

Krafft-Ebing's work does not describe BIID, but acrotomophilia- a fetish- somewhat similar to what we today call "devoteeism". This is a world away from BIID- please do not confuse the two. From my readings over the years on the various websites and blogs, I would disagree that most BIID sufferers are concentrated on upper extremity amputations. Most appear to involve the legs- can the author cite his sources for this? Also,

[Recommend?](#) (3)

[Responses](#) (2)

[Report](#)

[Link](#)

300 documented cases- I can tell you that there's more than 300 of us, but we're largely undocumented- we're secretive about our condition- only a few of us speak out about it.



**willothewhip**

31 May 2012 4:07PM

@MWheeler

Neuroplasticity isn't a case of "talking yourself into it" it happens at a subconscious level.

I'm sure you know that persistent thoughts, behaviour, environment, and many many other factors have been proven to remap neural pathways. It helps in healthy development and learning and also recovery from injury, i.e it's part of the growing process in us all.

You say your body felt wrong at the age of 6. But lets face it, we all go through a similar phase at some point in our lives, usually through puberty, but 6 years old !. Are you sure your not confusing idle curiosity of an alternate lifestyle or personal empathy with a desire ? And as the years passed this developed into a full blown yearning due to a lack of guidance and restraint or even a simple fantasy (sexual or otherwise).

Or are you saying you had this strong desire to be disabled as a 6yr old even though at the time you couldn't process it ? You have to realise that a child's brain is very susceptible to external factors, and if there are issues with insecurity and self worthlessness etc etc, then it's very natural to seek solace it whichever area it can find it. Perhaps in your case, for whatever reason, that just happened to be disability.

You also say this mismatch was answered when you saw an amputee, yet in a previous comment you say you desire paraplegia. They're VERY different forms of disability, where's the connection ? other than it being a disability and having similar mobility issues. You do realise that the human brain is designed to look for and find patterns in everything it encounters, it's part of the evolutionary process of fight or flight, is it friend or foe. If it's a friend and you find comfort in imaging yourself with a disability then you'll welcome it, develop a relationship with it, and then, who knows, maybe one day you'll want to become it.

No doubt you've had issues with regards to the desire, but is that the internal images fault or the desire for it i.e not having it.

In life we've all got things we want, things we really really want, but what gives us a right to demand any of these things. Life doesn't owe us anything, we simply have to accept what we're given, and make the most of it. Rather like a disability in fact.

[Recommend? \(2\)](#)

[Responses \(1\)](#)

[Report](#)

[Link](#)



**MWheeler**

31 May 2012 7:06PM

Response to [willothewhip](#), 31 May 2012 4:07PM

Yes, this is true- neuroplasticity is the formation of neural

[Recommend? \(1\)](#)

[Responses \(1\)](#)

[Report](#)

[Link](#)

pathways, a process of cerebral growth. I don't deny that. Sometimes those pathways get interrupted. I don't think it's always a product of environment- sometimes things just go wrong. Neuroplasticity extends beyond infancy- we are constantly learning, creating memories, and developing responses to stimuli. In this, "talking yourself into" something can be related to neuroplasticity, whether it falls into a rigid definition or not (agreed- I have an unqualified opinion...).

And, yes- it was the age of 6 that I didn't feel correctly connected to my body (for lack of better terms). Something was wrong, I couldn't identify it, but it was clearly there. Deny it if you wish, but you can't take my experiences away from me- something was definitely wrong with how I perceived my body. A sexual fantasy at that age is unlikely (as far as I know...).

A missing leg represented lack of knowledge of its presence, lack of its sensation and the ability to move it. Yes, a missing limb is far different from paralysis, but I identified with the deficit- not necessarily with the physical manifestation of the specific deficit. At six years old, the concept of paralysis was outside my realm of imagination- my only understanding would be "missing", "not there", "can't feel it". How cognizant should we expect a child to be? You're right- I couldn't process it- but it was there, how could I have had a curiosity about something for which I had no concept? From that, paralysis and its lack of sensation or movement can compare with limb loss- even if it's a round about approach.

"the human brain is designed to..." "it's part of the evolutionary process..." So which is it? By design or evolutionary process? Fair is fair- if you're going to point out my contradictions, I'll point to yours. "Fight or flight" is inherent to all life, a necessity to assure propagation- I'd say that it's by design.

In life, we also have things that we don't want and can't shed it's load. Life owes us nothing, and truly no one has a right to anything. All I want would be an end to the frustration- regardless of having a right to it or a right to get rid of it. Indeed, it is a disability.



**Neuron26**

31 May 2012 8:12PM

Response to [MWheeler](#), 31 May 2012 2:41PM

Yes, the Penfield map or homunculus is a well accepted part of current neuroscience. Ramachandran's claim is that there was a discrepancy between the Penfield map (which was complete) and the body image map found in the parietal lobules. This argument makes sense IF you accept the notion that there is a localized, higher order, body image map in the parietal lobules. This notion was abandoned decades ago. There is a 2007 article in Primary Psychiatry by Michael Trimble that discusses the history of the body image notion. The MEG results that Ramachandran obtained (for one or two subjects) actually suggest a different explanation for apotemnophilia. There may be a problem with

[Recommend?](#) (3)

[Responses](#) (2)

[Report](#)

[Link](#)

"feeling" movement in the limb. It is typical of Ramachandran to provide a highly speculative explanation that is not based in current neuroscience. That is, he is good at presenting ideas that would have been more plausible twenty years ago.



**MWheeler**

31 May 2012 8:21PM

Response to [Neuron26](#), 31 May 2012 8:12PM

@Neuron26: Thanks for making that clear. My apologies for the misunderstanding.

[Recommend?](#) (0)

[Responses](#) (0)

[Report](#)

[Link](#)



**Moheb**

31 May 2012 9:02PM

Response to [Sssssssssssss](#), 30 May 2012 7:10PM

BIID certainly cannot be explained as attention-seeking behaviour, and it's not like body dysmorphia, as you suggest in the penultimate paragraph. As far as I know, most sufferers report being happy once the affected limb has been removed - if, that is, the amputation is done at exactly the right location.

[Recommend?](#) (2)

[Responses](#) (1)

[Report](#)

[Link](#)



**Sssssssssssss**

31 May 2012 9:09PM

But you have to admit, that a mis-matched body is one whose limbs are missing.

Just in case your brain doesn't recognise a limb as part of the body, then is this a problem of the brain, but not of that limb. The limb is correct, since nearly all humans have got 2 arms and 2 legs. The brain has got as fault if it can't accept that limb.

That's like that case in America with Zimmerman and Martin. Who was right? Was it okay to shot Martin? Was he a threat? I don't think so. Only Zimmerman thought so and killed him. But I think Zimmerman was wrong.

And if we could ask your limbs now whether they are a threat, they surely would say "no". They surely would claim that they are a part of this body and that they are allowed to be there. They would say, that only that brain up there wants to get rid of them - for whatever reason.

So, and if I was a judge, and if I had to decide who can stay and who has to go, I would decide that the limbs (or Martin) can stay and that the brain (or Zimmerman) has to rethink his behaviour.

Ask your limbs what they think about the matter!

[Recommend?](#) (2)

[Responses](#) (0)

[Report](#)

[Link](#)



**Sssssssssssss**

31 May 2012 9:13PM

Response to [Moheb](#), 31 May 2012 9:02PM

This comment was removed by a moderator because it didn't

abide by our [community standards](#). Replies may also be deleted.  
For more detail see [our FAQs](#).



**Moheb**

31 May 2012 9:33PM



Response to [Neuron26](#), 31 May 2012 8:12PM

Here's the 2007 article you're referring to: [Body Image and the Parietal Lobes](#). I disagree that the notion of a localised body image map in the parietal cortex "was abandoned decades ago." Ramachandran isn't the only researcher who associates SPL with bodily representations - see [Wolpert et al \(1998\)](#) and [Naito et al \(2007\)](#), for example.

[Recommend?](#) (0)

[Responses](#) (2)

[Report](#)

[Link](#)



**MWheeler**

31 May 2012 9:43PM

@Ssssssssssss: Absolutely- the brain is at fault, nothing wrong with the limbs. Psychotherapy does not change the issue, pharmacotherapy doesn't fix it, either. Psychotherapy and elective surgery are both difficult to find- most psychotherapists are unfamiliar with the condition and surgeons are loathe to lop off a viable limb- we're screwed at both ends.

The nearest parallel to BIID is Gender Identity Disorder (GID), yet we see scores of gender reassignment surgeries every year. Trying to convince a GID person that their sex is correct is also telling us that our bodies are correct- it just won't happen! Given that, what's easier to fix- the mind or the body?

[Recommend?](#) (0)

[Responses](#) (1)

[Report](#)

[Link](#)



**willothewhip**

31 May 2012 10:04PM

Response to [MWheeler](#), 31 May 2012 7:06PM

1) I'm certainly no neurology expert either, and as far as I'm aware neuroplasticity is quite a contentious subject, in that it's more of an umbrella term for many differing aspects of development and growth within the brain. Perhaps Mo would be the best person to explain.

2) No, I certainly don't have any rights to deny what's going on in anyone else's brain, I'm just questioning the interpretation of these experiences. One invariably thinks one is correct, until one is proven wrong. Then it's up to that individual to decide if they'll accept the correction or not. However, it's worth remembering that BIID is not an officially recognised condition, not to deny its existence, rather, there simply hasn't been enough study of this disorder to clarify it. Therefore no one really knows the who, why, where, and what it really is. Which in turn leads me to the conclusion that at this stage it would be a mistake to allow elective surgery, regardless of the suffering involved of those who have it. That may be harsh, but I'm also very very concerned about the social, ethical and moral issues this brings. If society

[Recommend?](#) (1)

[Responses](#) (1)

[Report](#)

[Link](#)

feels the need to provide a happiness quota for every individual that demands it, then as someone above said, let the NHS hand out cheques to everyone who hasn't won the lottery.

3) You must have had an awareness of disability as a 6yr old, and a 6yr old, by nature, has a seeking mind. It's not too much of a leap to suggest your curiosity may have been pricked by a sighting of a person with a disability or something you saw on TV. But what i question is, the depth of that feeling at that age may have started as idle curiosity, but then grew into a deep personal desire in the intervening years, due to other influences. Now what those influence may be i have no idea, but is there a chance those influences perhaps sent you down a path of personal desire rather than personal empathy ? If you suggest that a pre-programmed body-map was the culprit, then is there evidence of that ? evidence that can't be explained by neuroplastic learning ?

And trust me, i know all about paralysis, and to connect it to amputee-ism really is a long long way around. I accept what you're saying, but, as far as i'm aware amputees don't loose bowel or bladder control, or sexual function, don't suffer from pressure sores or osteoporosis or many many other things. But my question in that instance was, you saw an amputee, thought that makes sense, but i'd like a lil bit more. Why not a quadruple amputee, or a tetraplegic ? Or are you under the assumption this mismatched image in your brain is most definitely a paraplegic. Is so, how do you know ?, are you playing it safe ?, do you want a disability that doesn't affect your sexual organs ? doesn't effect your daily life to the point where someone else has to feed you, dress you, wipe your arse ? Why do you get to choose, and those who've become disabled by accident, birth or disease don't.

4) Lets not argue about semantics, evolution does contain a fair amount of design within it, just not from...no let's not go there.

5) Yes i can understand the frustration, but believe me, if you ever achieved your desired disability you're entering a whole new world of frustration. It may make you happier for a period of time. But, there's no turning back, it's for life, and it's a shortened life too (paralysis). There are other ways to curtail the frustration, but they require both an effort and a desire on your part to see them through. Is it possible you've reached a point where you regard elective surgery as the easy option ? If so, is that a reason to demand it ?



**Moheb**

31 May 2012 10:18PM



Response to [MWheeler](#), 31 May 2012 3:39PM

I don't doubt there are far more than 300 BIID sufferers, but that's roughly the number of cases that have been documented in the medical and scientific literature. Michael First told me that he has interviewed over 200 himself. As for acrotomophilia, that term was coined by John Money in his 1978 paper. He distinguished it from apotemnophilia (the old name for BIID),

[Recommend?](#) (0)

[Responses](#) (1)

[Report](#)

[Link](#)

but as stated above, I think an attraction to amputees is a mild form of BIID.

Thanks for sharing your experiences and thoughts. I'm glad you liked some aspects of the article.



**Sssssssssssss**

31 May 2012 10:33PM

Response to [MWheeler](#), 31 May 2012 9:43PM

And why don't surgeons cut off the limbs?

Because that would be insane, and they don't want to do that. So you can hardly blame them.

And if a psychotherapist couldn't help you, then try another one or try to fix it yourself. Billions of people solve their problems without psychotherapy.

My mother would say now, that you have walked the wrong way. And obviously, you have been running that wrong way for many years. And now you cannot admit, that your obsession was a really stupid idea. You would be disgraced to the bones. It's the hardest thing to admit a mistake. You have tried for ages to prove that your limb isn't a part of you, and now you can't suddenly say: "I've changed my mind, I love my limbs now". So you are trapped in a pitfall that you have build yourself many years ago - probably when you were still a (stupid, little) child.

Though, I can tell you, that nobody will laugh at you if you accepted your limbs now. In the contrary, they would be relieved, because diseases are always a burden for the relatives too. You probably don't see that, because relatives don't talk about their own problems in the presence of a sick person. But I am sure they would be really happy if you helped them doing the dishes or the shopping with your healthy limbs.

[Recommend?](#) (1)

[Responses](#) (0)

[Report](#)

[Link](#)



**MWheeler**

31 May 2012 10:59PM

@Sssssssssssss: You clearly illustrate the point that you have absolutely no understanding of the issue, are unwilling to learn more about it, yet maintain your bigoted opinion. How do you dare to tell me I've made a mistake when you have no understanding of the issue?

By the way- I do most of the grocery shopping, wash the dishes, feed the animals, run the Hoover, clean the bathroom, paint the porch, change the oil in the car, do the laundry...

“There is much to be said in favour of modern journalism. By giving us the opinions of the uneducated, it keeps us in touch with the ignorance of the community.” (Oscar Wilde)

[Recommend?](#) (3)

[Responses](#) (1)

[Report](#)

[Link](#)



**MWheeler**

31 May 2012 11:18PM

Response to [Moheb](#), 31 May 2012 10:18PM

[Recommend?](#) (1)

[Responses](#) (0)

[Report](#)

@Moheb: 300 is paltry, but given that so many of us are in hiding, a low number of documented cases may be in order. As far as devoteism (acrotomophilia) is concerned I think you'll find heated opposition in the BIID community regardless of your suspicion. We're more open to relationships with disabled people, maybe from our heightened awareness of various disabilities. There's always an initial physical attraction first and emotions follow. From that, I can understand your opinion, but don't believe it to be necessarily true that it is a lesser manifestation of BIID.

I wish I had known of John Money- he was a professor at Johns Hopkins University in Baltimore, the city where I grew up.

I don't agree with some points of your article, but I do appreciate the mostly constructive discourse it presents. Of course, all opinions expressed are my own and don't necessarily represent those of others. We all have questions, and as someone with BIID I hope I can contribute to further understanding of the disorder. This is my pleasure.

[Link](#)



**Sssssssssssss**

31 May 2012 11:27PM

Response to [MWheeler](#), 31 May 2012 10:59PM

This comment was removed by a moderator because it didn't abide by our [community standards](#). Replies may also be deleted. For more detail see [our FAQs](#).



**MWheeler**

1 June 2012 12:41AM

Response to [willothewhip](#), 31 May 2012 10:04PM

@willothewhip:

Thank you for the conversation! I like your questions.

1: I'm not a neurologist either, that's a bit too far over my head. Mo may be an authority on neuroplasticity, but not on BIID.

2: The interpretation of those experiences is something I have difficulty with myself. I've spent far too much of my life in self examination, looking for causes, looking for reasons, and examining reactions. If I had the answers, would it go away? A mature mind should be able to accept that correction, but as it stands now I can't really find resolution or reason to any of it. All I can say is that I've fought with it for most of my life, denied it, tried to ignore it, and have it increase in intensity over the years. There is an effort in the US to have BIID included into the DSM-V (Diagnostic and Statistical Manual, revision 5). We'd like to have some sort of means to codify it, analyze it, eventually treat it. As it stands now, BIID is an orphan diagnosis. As far as no one really knowing what it is, all we can present is our long list of symptoms, no concise cause. I disagree on your statement that elective amputations being a mistake, as there is a body of evidence to suggest otherwise. To the moral and ethical

[Recommend? \(1\)](#)

[Responses \(1\)](#)

[Report](#)

[Link](#)

questions, yes- these are difficult questions to answer- and this blog page isn't big enough to contain all of it.

3: I don't know. I just don't know. Another kid with a cast on his arm? Image on the television? No, I can't say I was aware of any disability until that one instance. Perhaps an emotional shock? I don't know... I wouldn't say a pre-programmed body map, either- but clearly a faulty one, but how can evidence of that be presented other than expressing my experiences as I'm doing here? Whether it's attributed to neuroplasticity, who can say- it very well may be the case. Regardless, it's been kicking my ass for 48 years! A point of contention, though- you can't possibly know *all* about paralysis until you *experience* it. I know, I did take a long way around in my connection to amputation. We with the paraplegic manifestation of BIID are aware of all these issues, we know they happen, we know they're unpleasant and even life threatening. Why paraplegia and no other manifestation? We just know- there is a line of demarcation to it- we know a boundary to it. As the author states- "to the millimetre". And we do have those with quadruple amputation manifestations, quadriplegic (tetraplegic) manifestations, and so forth- even sensory BIID (blind and/or deaf). There are those who have electively had all their teeth pulled. This is a spectrum disorder. We know our boundary lines- what stays, and what goes. Yes, I do have a paraplegic manifestation of BIID- It's clear to me, and not an assumption. Effects to the sexual organs and bowel control are part of the package, unpleasant as they may be. "Why do you get to chose?"- Do you really think this is by choice? I didn't ask to have BIID, I don't like it. But here's the dichotomy to the thing- I really don't *want* to be paraplegic- I want (actually *need*) to have congruence between mind and body. Consider it a heated argument between mind and body, both insisting they're right! It's a fully blown raging battle!

4: Truce accepted

5: I'm aware that I'm trading one frustration for another. I just figure that I was born to be frustrated and resign myself to it. The decision, if executed, is irreversible- I grant you that. I wouldn't go as far as to say that surgery would be an "easy" option, not by a long stretch. My family is aware of my BIID, it isn't a secret to them. If surgery became an option to me, I wouldn't proceed without their consultation, but I would weigh it against the fact that I'm the one living in this body, not them. Yet again, is the suffering of the one (myself) enough to justify the sorrow of others (my family). It would be a selfish decision to proceed, but I've also become so sick and tired of fighting. I want treatment for this- yes- I think it's a justifiable demand. If there were a psychiatric treatment that would cure this, or a pill to take, or ultimately surgery, it's a condition that justifies treatment.



**Neuron26**

1 June 2012 12:51AM

Response to [Moheb](#), 31 May 2012 9:33PM

[Recommend?](#) (1)

[Responses](#) (1)

[Report](#)

First, let me say that I think Ramachandran's conjecture that there is a neurological explanation for apotemnophilia is closer to real science than many of his theories about mirror neurons, autism, and metaphors. If you look at the experimental work he has done there is a disturbing lack of evidence. Ramachandran often relies on data from one or two subjects. And in the case of his initial theory about phantom limbs his experimental work failed to replicate. But getting back to the issue at hand. As I read the abstract of the Wolpert paper from 1998 it makes the point that "Our findings suggest that the superior parietal lobe is critical for sensorimotor integration, by maintaining an internal representation of the body's state." This is what I was getting at when I said that people who suffer from apotemnophilia may suffer from an inability to feel movement in the limb they wish to have amputated. I am not a neuroscientist but I believe that this article is placing its emphasis on the notion of impaired sensorimotor integration. Ramachandran is pointing toward a defective internal representation, which he claims to have measured using MEG. The neuroscientists I have spoken to have suggested that Ramachandran does not understand the implications of the data he has actually generated.

[Link](#)



**Halotosis**

1 June 2012 1:28AM

Response to [Neuron26](#), 1 June 2012 12:51AM

His model may not be 100% accurate, it's very theoretical. Both theories revolve around the same region of the brain and a deficiency of that region.

I have paraplegia BIID, I need to disclose that. I've always felt wrong in my own body, I can not recall a time where I did not feel this way.

I came up with a theory on BIID based on my own experiences. That part of my brain was not processing the signals from my lower body properly. That this defect in my brain was causing so much disruption that it resulted in a form of neuro-psychological limb rejection. As I've gotten older, it's gotten worse and more obvious. The only thing I didn't have a way to ascertain was what part of the brain.

Ramachandran's theory seemed to match closely with my own. I met with him and his team at USCD for some research a while back. We did some experiments, ones I should try to replicate at home. They really helped me understand that something is definitely wrong with the way the signals from my legs are being processed. Even if they are not absolutely correct, they really did help me in understanding what's going on and why my legs feel so wrong to me. His theories are not without merits, based on my own experience.

If the superior parietal lobe is critical for sensorimotor integration, that could explain the involuntary muscle movements I developed about a year ago (myclonus). I've often said my legs were out of sync and disconnected from the rest of

[Recommend? \(0\)](#)

[Responses \(0\)](#)

[Report](#)

[Link](#)

my body. My own theory has evolved such that the feedback loop between the legs, motor cortex and parietal lobe IS out of whack. Of course, the myoclonus might not be related at all.

In any case, that's how science works. With a disorder like BIID, finding people willing to let you experiment on them is difficult. Not many of us are willing to be guinea pigs, so a lot of research is going to be based on a very small sample size. Theories evolve as we gather more data. Hopefully one day we'll have an actual answer.

And it's nice to see such intelligent discourse on the subject. Usually these things devolve into something I won't participate in.



**Sssssssssssss**

1 June 2012 1:28AM

Response to [MWheeler, 1 June 2012 12:46AM](#)

This comment was removed by a moderator because it didn't abide by our [community standards](#). Replies may also be deleted. For more detail see [our FAQs](#).



**Sssssssssssss**

1 June 2012 1:55AM

BIID is a term that covers several conditions in which people feel their body-image does not match with their body shape.

That is applicable to 99.9% of all humans.

[Recommend?](#) (1)

[Responses](#) (0)

[Report](#)

[Link](#)



**Sssssssssssss**

1 June 2012 2:13AM

This comment was removed by a moderator because it didn't abide by our [community standards](#). Replies may also be deleted. For more detail see [our FAQs](#).



**Sssssssssssss**

1 June 2012 3:06AM

This comment was removed by a moderator because it didn't abide by our [community standards](#). Replies may also be deleted. For more detail see [our FAQs](#).



**Hanceni**

1 June 2012 2:40PM

From a left-wing socialist ethical perspective, voluntarily cutting off one's limbs and voluntarily cutting off one's genitals are fundamentally different. This is because cutting off one's limbs affect one's social function, for example in work, whereas cutting off one's genitals does not. Cutting off one's genitals only affect reproduction and sex. Morally speaking all people have an

[Recommend?](#) (0)

[Responses](#) (2)

[Report](#)

[Link](#)

obligation to work for society in general, but people do not have an inherent moral obligation to reproduce. People can choose to not reproduce if they want. Otherwise one might as well oppose feminists who support voluntary unconditional abortion. All people should have the right to self-sterilise if they wish. Furthermore, society has no right to dictate what goes on in people's own bedrooms. The only moral obligation people in general have towards society is in terms of work and paying taxes.



**Halotosis**

1 June 2012 4:44PM

Response to [Haneen1, 1 June 2012 2:40PM](#)

A recent, major study on BIID found that people who had the offending limb removed scored lower on the disability scale than those who did not. In other words, they were more productive and capable AFTER removal of the limb. The presence of the offending limb causes us so much distress we can't function. If people with BIID are more productive AFTER surgery, then your whole argument is moot.

Also, it seems to be a common misconception that everyone with BIID wants to have surgery. Some of us just want it to be socially acceptable for us to use assistive devices to alleviate the discomfort we live with.

<http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0034702>

[Recommend? \(0\)](#)

[Responses \(0\)](#)

[Report](#)

[Link](#)



**MWheeler**

1 June 2012 5:56PM

Response to [Haneen1, 1 June 2012 2:40PM](#)

A disability does not necessarily hinder a person from participation in society. There are a large number of jobs that are done sitting at a desk. If you use a chair at a desk anyway, does the actual type of chair matter? Even assembly line automotive manufacturing workers work from a chair. If we were in a primarily agrarian society, I would agree with you.

Some jobs are definitely inappropriate for wheelchair users- building construction, waterworks engineers and the like- but there are many able bodied people can't work those positions, so I don't really see that disability has any relevance to overall job performance.

Lower limb amputations pose the least obstruction to job performance, but you'd also be surprised at how much stuff I can pile on my lap when returning from the grocers. Carrying objects, even heavy ones, pose little difficulty to wheelchair users. There is one thing that does stick out and a major obstruction, and that being upper limb amputees. The standard type Dorrance hook or work hook can never replace a biological hand! In this case, I do see upper limb deficits as a clear hinderance to job performance, despite the availability of

[Recommend? \(0\)](#)

[Responses \(0\)](#)

[Report](#)

[Link](#)

assistive technology.



**Neuron26**

1 June 2012 6:13PM

Response to [Moheb](#), [31 May 2012 9:33PM](#)

Thanks for posting the articles. It helps orient the discussion toward current neuroscience. I wanted to give you a direct quote from Ramachandran's recent remarks on Edge (02-21-12) Ramachandran used MEG scanning to determine that the Penfield map was complete and then in a second experiment he used galvanic skin response measurements to determine if there was a difference between areas that the subject wanted amputated and areas of the body that felt normal.

Ramachandran states:

"Then, of course, we went straight to the brain and we said let's map it out. And as I said we found S1 was normal, if you go to S2 that's normal. If you go to the superior parietal lobule where the body image is constructed, to some extent the inferior parietal lobule, right parietal, let's say, where the body image is, there is no arm representation in that center. That's what we found."

Ramachandran is claiming that a difference in galvanic skin response indicates that there is an incomplete body image in the parietal lobule. This strikes me as an example of attempting to fit the experimental evidence to a theory that is both vague and overly simplistic. But it does make for exciting press releases.

[Recommend?](#) (1)

[Responses](#) (1)

[Report](#)

[Link](#)



**Halotosis**

1 June 2012 6:32PM

Response to [Neuron26](#), [1 June 2012 6:13PM](#)

Actually, that is NOT what he is saying. What the GSR indicates is an emotional response to the given stimulus, it DOES NOT indicate what is malfunctioning. It's a measure of stress of the subject. It's the exact same theory behind polygraph machines.

His theory on BIID is that because of the miswiring of the super parietal lobe, stimulus is instead causing activation in the emotion distress region of the brain. The GSR is a measurement of the distress caused by something like a pinprick. What he found was that in people with BIID, the GSR shows that there is a direct correlation between stimulus and emotional distress.

[Recommend?](#) (0)

[Responses](#) (1)

[Report](#)

[Link](#)



**MWheeler**

1 June 2012 8:22PM

Response to [Halotosis](#), [1 June 2012 6:32PM](#)

A *distress* response... Accounts for the frustration, aggravation and depression? Even feeling my trouser legs and socks against my skin is annoying to me. Interesting thought...

[Recommend?](#) (0)

[Responses](#) (0)

[Report](#)

[Link](#)



**willlothewhip**

[Recommend?](#) (0)

  1 June 2012 9:14PM

Not sure why but the website won't let me reply to individual posts. Couple of quick points.

@Halotosis

You say those who've had a limb removed have scored lower on THE disability scale. But there are hundreds of disability scales, which one are you claiming is THE disability scale ? The Sheehan scale, the Kurtzhe scale, the Stanford HAQ scale, the DIsability Status scale, the Quebec Back Pain disability scale, etc etc ? We're not buying double glazing here, we're just looking for transparency and unbiased information.

Also you say the stimuli below the line of desired amputation causes activation in the emotional distress region of the brain. Now i'm no neuroscientist, in fact i'm taking a bit of a crash course in it as i speak (via google) However, unless i'm mistaken, i believe the emotional distress area of the brain uses the exact same brain circuitry as those used by emotional desire and pleasure. I find that fascinating.

Could it be possible that these desires for elective disability can swing from fear and loathing to pleasure and excitement from one moment to the next ? Could it be the mere thought of having a specific limb removed at a specific level is activating the desire receptors in the brain, and depending on the emotional state of the person at the time, can then trigger distress, fear, excitement or pleasure ? And the fact that this is taking place in the desire receptors themselves makes the desire even stronger ?

Worthy of more thought ? or have i boarded the wrong boat and currently heading to china, slowly ?

Can any qualified neurologists confirm or deny any of that ?

@MsWheeler can we continue our multi questioned mini epic a little later ? long hard day at work, would like a drink or two right now.



**Halotosis**

1 June 2012 9:36PM

Response to [willothewhip](#), 1 June 2012 9:14PM

I provided the link to the report. You can read it for yourself, they mention their methods and what scale they used.

[Recommend?](#) (0)

[Responses](#) (0)

[Report](#)

[Link](#)



**willothewhip**

1 June 2012 11:00PM

So 7 individuals who had a (non specified) limb removed scored lower on the Sheehan Disability scale than those with BIID. It's not exactly the most exhaustive questionnaire you'll ever come across [http://www.cqaimh.org/pdf/tool\\_lof\\_sds.pdf](http://www.cqaimh.org/pdf/tool_lof_sds.pdf)

Is that a strong enough foundation on which to build an argument justifying elective surgery for those who wish to have

[Recommend?](#) (0)

[Responses](#) (2)

[Report](#)

[Link](#)

MS, all four limbs removed, to become blind etc ?



**Sssssssssssss**

2 June 2012 12:28AM

This comment was removed by a moderator because it didn't abide by our [community standards](#). Replies may also be deleted. For more detail see [our FAQs](#).

Comments on this page are now closed.

© 2012 Guardian News and Media Limited or its affiliated companies. All rights reserved.

;