

**Right: Alex Mensaert, a triple amputee who runs several amputation focussed websites**

**I**n 1992 George Boyer put a shot gun to his knee cap, pulled the trigger and never looked back. He is heralded as one of the first successful men to fulfil his desire of becoming an amputee. Since then, many other men and women have followed in his (now half prosthetic) footsteps - though not all by such drastic means - and form part of a guarded community obsessed with amputation. Body Integrity Identity Disorder (BIID), is a medical condition whereby sufferers believe that their anatomical identity is not representative of the way they think they should look. In short, they are burdened by the overwhelming belief that they should be an amputee.

The subject was first addressed from a medical perspective by John Money in 1977, who defined the condition as Apotemnophilia (which literally translates from Greek as 'amputation love') and rooted its motives in sexual arousal. Disagreeing with this diagnosis, further work has since been completed in an attempt to explain the real causes, but the limited research in the field has left the disorder undefined - it falls under no official medical categorisation - and no ultimate reason can be given for why someone would wish to mutilate their body in such a way.

Further distorting the subject are other varieties of amputation obsession, for which colloquialisms have emerged. A 'wannabe' refers to someone who wants to become an amputee, while a 'pretender' prefers to play the role of an amputee by such methods as tying one leg behind them or using a wheelchair. Slightly more disturbing are 'devotees' who are sexually attracted to amputees, if not to people with a variety of disabilities.

I am a congenital amputee - a term I was unfamiliar with until I started researching this article - born without my right hand. Having never been dissatisfied with my physical state (apart from longing to play the piano and wear evening gloves), I see no difference between amputees and the rest of the world. But I still struggle to understand why someone would choose to dispose of a limb that would be so dear to me.

The man that all arrows point to for expertise on the subject of BIID is Dr Andrew Jones, the only British doctor known to have carried out two amputations on men who had no physical ailment.

# BORN TO BE DIFFERENT

The world of self-demand amputation is mysterious and guarded. Nicky Ashwell infiltrates this elusive community to question the motives, the methods, and the rationale behind choosing to be less than whole.



Dr Jones first became aware of BIID in 1997, when an acquaintance put him in touch with a ‘wannabe’. His initial reaction was, “It struck me as being quite extraordinary that anyone would actually want to have limbs removed because most people that I do amputations on are absolutely devastated by it.” Instantly intrigued by the condition, Dr Jones met with the potential amputee and his wife to discuss the implications of what was being requested, before insisting on the completion of some psychiatric tests. “I was actually quite impressed by the fact that they [the psychiatrists] said that as far as they could make out there was nothing psychotic about the guy, he wasn’t mentally ill in the accepted psychiatric tests of it and he was entirely aware of what he was requesting.”

Following the correct channels Dr Jones received approval for the operation and made his patient a happy man.

The cost of the operation was £3000, however Jones took no personal fee for completing the surgery. It took little time before the story of the successful wannabe caught the attention of the amputation-longing international population and a second operation was carried out shortly afterwards. Jones’ reputation was attracting not only a queue of wannabes but publicity, too. It was the public outcry aroused when his actions became known to a local MP that prevented him from proceeding with any further operations. Although nearly ten years have passed since this controversial operation neither Dr Jones, nor any other surgeon, has completed a similar amputation.

The negative publicity of that case seems to have driven a community of wannabes on the brink of finally becoming public, underground, to the secretive recesses of the internet. There they seek shelter in such websites as [www.ampulove.com](http://www.ampulove.com) run by Alex Mensaert. “I started Ampulove to give people more information, certainly medical information” says Mensaert, a 37 year old triple elective amputee from Belgium. He is one of few successful wannabes prepared to discuss his experiences openly and is admired by the DPW (devotee, pretender, wannabe) community for it.

“People sometimes call me a god of amputations,” he says, “I don’t like that word but I only want to prove that it’s really possible”. Mensaert is thoroughly aware of how difficult it is to be accepted as a wannabe and likes to think that Ampulove helps others come to terms with their feelings in a friendly environment. “To most people, it takes time to discover that they are not alone. It is certainly not a subject people want to talk about”. There are more people keeping secrets about amputation desires than you might expect. According to Mensaert, Ampulove is a hugely popular website attracting up to 800,000 members (though whenever I log on there seem to be no more than six online), all of whom pay a membership fee starting at \$4.95 for two days and reaching \$100 for a year.

The reluctance of these people to come forward appears to be hindering the development of medical understanding regarding BIID. In a study carried out by psychiatrist Dr Michael First in 2004, only 52 participants were prepared to be questioned - and that was over the phone. First’s study was the first instance of the use of the term BIID. Out of his 52 subjects, 15% cited sexual arousal, 63% restoration of true identity and 37% a limb feeling different,



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as reasons for amputation. Six people had tried to amputate their own limb.

“My impression was that by and large, contrary to what you’d expect, these people are relatively normal, which was a surprise”, says Dr First, who was introduced to BIID because of his work editing the Diagnostic and Statistical Manual of Mental Disorders. It strikes me that if a psychiatric expert suspected less than normality from these people it is no wonder that the general public hold negative preconceptions. First’s comments concur with the assurance Jones gave me that his patients were “well oriented, sensible and not neurotic”, suggesting that we should consider re-assessing our initial prejudices.

My first suspicion of why it is difficult to come to terms with wannabes is the inability of BIID to shake off its sexual connotations, a problem which not only mars perceptions of the disorder but also



**Above: Alex Mensaert with one of his prosthetic limbs. Left: Psychiatrist Dr Michael First who coined the term BIID**

interferes with psychiatric research.

According to Jones, “there is a very common perception that this is a sexual disorder and therefore should not be regarded as a medical problem. I think there is a major misconception by the general public about it and partly I think it is fuelled by the number of websites there are that are sexually related”. Jones cites the infiltration of sites supposed to be about BIID by apotemnophiles, as a reason for the disorder’s sexual stereotyping. Unfortunately he is right. It took me hours of internet searching before I learnt the correct terminology to use so that my results displayed medical information instead of pictures of naked amputees.

Mensaert however, is a self-proclaimed apotemnophile, unashamed of admitting that being an amputee makes him more sexually satisfied. It is this desire that has led him to be in the physical state he boasts now. “There are a lot of wannabes,” he says, “and they go on and they go on, just like me, and when you see me - I have no legs and I have one arm”. Mensaert’s websites (Ampulove is just one of twelve) are geared towards fulfilling sexual desires. He sells DVDs of himself (type ‘amputee Alex’ into You Tube for examples) and

provides a platform for amputee models to publicise themselves.

When I speak to Dr First regarding his opinions on Apotemnophilia he provides rationale that completely alters my opinion. “If it was just about people who are turned on by amputation it wouldn’t be a very interesting disorder because people can be turned on by anything”, he says. He provides a sudden reminder that it is easy to be shocked by sexual deviations when you’re brought up a prudish Brit. On further contemplation it occurs to me that although admission to being sexually attracted towards amputees would cause a scandal in most circles, it is only a symptom of our overall negativity towards people with disabilities. If we see disabled people as just that - unable, incapable - it is no wonder the concept of a devotee sparks controversy.

It is for this reason that I have been less shocked by BIID than my four-limbed friends. I am able to see beyond the taboo of disfigurement that I’m sure clouds many peoples’ perception and my amputee friends feel the same way. As Mensaert tells me, “they see it as a disability but I do not feel disabled.” A sentiment I’m sure many disabled people would agree with.

Thus what is most mind-blowing about BIID is simply, as Dr First tells me, “the fact that sufferers want to have an amputation”, or rather as Mensaert puts it, “you don’t feel you’re complete with the legs, you feel you’re complete without the legs.” It is this seeming disregard for body parts and the paradox of being ‘whole’ without a full complement of limbs, which is hardest to accept. The language I have noticed throughout my research reflects this complacency. “Get rid of his leg” is used by Mensaert as if he’s discussing a grotty old caravan parked too close to his garden, “have his leg off” spoken by a nonchalant Dr Jones, and in a BBC Horizon documentary the narrator chooses the phrase “be rid of a limb”. The indifference for body parts indicated by these terms conflict with the cherishment I assume most people apply to their intact bodies.

Alternatively, Mensaert’s contentment with his new form is romanticised. He tells me how “it is a feeling you almost can’t describe because there is nothing in common with it” and goes on to relay stories of fellow amputees who experience “that nice warm feeling in their stump when they wake up”. He also discusses methods of “putting your limb to sleep”, as if it were a sickly pet that can no longer be part of the family. Notions such as this are so perverse it is hardly surprising that voluntary amputation is such an instant turn-off.

“Putting your limb to sleep”, refers to one of the many controversial methods used by wannabes to achieve their desired amputation. It involves injecting Xylocaine - a substance easily obtained on the internet - into the desired limb in the hope that it will be in an irreparable state by the time you reach the hospital. One of the more controversial pages on Ampulove details techniques for forcing amputation and includes: “Dry Ice Experience”; “More about the tourniquet method”; and “Freezing to Dead: another way to lose fingers or toes”. Mensaert is insistent that these have all been sent to him by medical experts who wish to remain anonymous. He tells me only a minimal amount about how he achieved his own amputations.

Dr Jones is very concerned about the extremes



**Left: Alex Mensaert using his wheelchair during his current stay in Florida. Below: the ‘wannabe’ section of [www.ampulove.com](http://www.ampulove.com)**



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**The wannabe horror stories range from sedation and chainsaws to lying across a railway line waiting for the ten o’clock train**  
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wannabes will endure to get what they need. “I’ve had quite a number of people who have self-injured to obtain what they want and I know of one woman who has frozen off both her legs”, he says. The wannabe horror stories are innumerable and range from sedation and chainsaws to lying across a railway line waiting for the ten o’clock train. They can all be regarded as a measure of the desperation felt by those with BIID, for whom, as Jones is keen to reiterate, “psychiatric treatment has no effect”. Dr Jones continues, “BIID sufferers have this lifelong torment which starts in infancy, in childhood, and lasts until they die.” “It’s connected with a childhood exposure to an amputee,” says Dr First, “There’s also some relationship between the amputee you see as a child and what your own desired location is”. I wonder if I have ever been the amputee to unleash this burden of desire onto such a child.

So, how are we to come to terms with this bizarre condition? To Dr Jones the most successful way to explain BIID is by drawing comparisons with Gender Identity Disorder. “I would say that these people have a lifetime agony about the desire to have their body image changed, they are exactly the same as people who have the GID and their life is just as tormented as these people.” Dr First agrees with this evaluation of the condition, “With GID you have the sort of people who feel like they were born in the wrong body, you know a man feels like he was born in a woman’s body and he wants to become her. So I’d say, well, it’s similar”. It is a persuasive argument. Is it really so much harder to comprehend that someone wants to become disabled than it is to accept a switch of sexes? In my mind it keeps coming back to the negative stereotyping of disabled people. As pleasant as it would be to believe that the public has

overcome its prejudices towards the disabled, the recently launched advertising campaign by Wallace & Gromit makers Aardman targeting just that, suggests otherwise.

Sure it’s fine to change from a man to a woman - they are virtually equal after all - but to disfigure yourself into the antithesis of the media images of perfection we are constantly bombarded by, is something else. We have no problem with a surgeon slicing up, pumping out or plumping up part of the body to improve our confidence, but only because we want to appear like the people we’re told are beautiful.

For a final perspective on elective amputation I contact The Limbless Association, a charity which provides support for people who are without one or more limbs, to see how they would react to someone who has chosen to become an amputee. Outreach Officer Alex Hyde-Smith assures me that the organisation would have no opposition to it. “We are here to help anyone one who has or is about to lose a limb”, he says.

There is then, acceptance available for wannabes. However, I can understand why both Dr First and Dr Jones have been insistent on their affiliation to BIID rather than the more shady Apotemnophilia. The greatest hindrance stems from the deadly cycle of secrecy and misunderstanding that is fuelled by wannabes scared to come forth and a consequently ill-informed medical and general public. In criticising these individuals, we underestimate the personal struggle they have undergone coming to terms with their desires, and the courage required to admit to themselves who they are or want to be. It is not that they want to be different; amputation is simply the only way that they can feel complete.

*Some names have been changed to protect identities.*