

# The same but different: A new reality following limb loss

Clare Uytman

Limb loss and prosthesis use create a new reality. Experiences are on a fluctuating spectrum from grief and shock to relief and gratitude, particularly where the limb removal relieves pain or limited movement. However, these experiences can vary from month to month, day to day, even hour to hour...

**A**t the crux of the variation in how a person responds to limb loss and prosthesis use is how the experience differs from their expectation or desired outcome. The changing sense of what people consider 'normal' and what they expect life to be following amputation carries a huge weight in their understanding and sense-making of their circumstances.

My work follows a phenomenological approach, attempting to unpick and understand this sense-making from the individual's perspective. It is this contrast, and often conflict, between the expectation and experience within the lived perspective, that can lead to the uneasy or uncanny element.

## **Unique normality**

Through limb loss, individuals must come to terms with a variety of new versions of themselves: pre-amputation, post-amputation, their ideal selves. There is a constant renegotiation of new personal identities alongside the maintenance of pre-amputation identities. This includes how they feel about their bodies, how they look, what they can do and their perceptions of their place within their lifeworld.



Getty Images

## Vanishing time

In *Uncanny Bodies*, Goldschmidt, Hadow and Mazanderani (2020) brought together a group of fiction writers, poets and academics from humanities and social sciences, to explore the concept of 'the uncanny' (find out more on p.xx). We were encouraged to find common ground and interests which could spark a train of thought. I met Jane Alexander and we began sharing thoughts and knowledge, shaping ideas for both her creative writing and my reflections on how the uncanny can be experienced and understood in my research. This culminated in Jane's story called *The Lag*, and my own contribution to the anthology reflecting on the uncanny in amputation and prosthesis use.

In *The Lag* (Alexander, 2020), Jane skilfully integrates our discussions of my research participants' experiences and other findings, and her own skill and ideas as a story writer, all with the sense of uncanny that flows through her story; from the uneasiness her characters exhibit to the feeling of uncanny within the city itself. There are many things that define life with an amputation, from the relationship developed with the healthcare professionals and a new reliance on technology. In addition, there are aspects which can feel out of your control, and which impact the user on a day-to-day basis. As Jane expresses in *The Lag*:

There are so many ways for time to vanish in this new life of hers. All the medical appointments, for a start. The extra minutes in the morning, getting ready to leave the house; in the evening, tending to rubbed and broken skin. But it's the lag that frustrates her most. Something about the almost-inevitability of it. The perfect crime; the theft of a second with every step. (Alexander, 2020, p.185).

Consideration of these myriad of elements which make up the experience of living with limb loss, and the priorities of each individual is essential in supporting them to achieve their own goals for adjusting to life after amputation, whatever they may be.

Discussions of post-amputation reality often involve considerations of 'normality', but this is an entirely subjective concept. A more specific, personalised 'unique normality' accounts for specific needs, expectations, and desires. When I discuss this with my research participants the phrase 'get me back to me' sums up this focus on personal goals and expectations. Some have a need to appear and function as close to their pre-amputation self as possible. For others, a clear set of priorities emerges, with a focus on specific areas that will allow them to function and fulfil the same roles as before – such as playing with grandchildren or walking with friends. One contributor encapsulates this with: 'as long as I can do what I want, function as I want, achieve what I want, then I am me'.

A person's unique normality is a core consideration in using a prosthetic device and weighing up the varying elements of function and cosmesis – the preservation of physical appearance. Certain cladding materials which may make the device look more realistic, can impede function. Some prosthesis users are happy to display their device and are confident that the functional ability outweighs any concerns of negative judgments from others, but this is certainly not the case for all.

Others feel wary of allowing others to see their device. They find it unnerving and think that having their device displayed is akin to revealing personal and intimate details. They will wear clothes that hide their device, even if this leads to discomfort. This constant sense of renegotiation and adaptation can lead to uncanny elements. Being me, but not quite myself, having to contend with others viewing me and treating me in this 'the same but different' way, can lead to inner conflict as people navigate through this change in their life.

Renegotiating the way someone views themselves may also require a renegotiation of their previously held understandings of disability. This can present a challenge if there is a conflict in terms of the way a person understands disability and the way they see themselves. This is not a static, stable understanding

but often fluid and varied according to context and circumstances. People vary in their acceptance and use of the term 'disabled' in their definition of themselves. For some this offered a self-identification which allowed them to make sense of their new lifeworld and find kinship within the disabled community. Others appeared to reanalyse and adapt the term and their understanding of it to fit their view of themselves.

### Adjusting and readjusting to technology

Devices can maintain a level of functionality equal to pre-amputation, but can impede lives if they do not function adequately. A well-functioning, well-fitting device becomes part of the body, allowing people to function without thought or limitation. However, some feel controlled by the device and by the system they rely on when things go wrong. If the device is broken, or not fitting as it should, it must be relinquished for repair. This entirely limits the individual who must now compromise their activity or find an alternative and often less agreeable solution such as using a wheelchair or crutches, which immediately impacts

where they can go and what they can do.

This often has an impact on how other people treat them, leading to frustration at being treated differently on days using a wheelchair compared to days using a prosthetic device. As a result, people often self-manage their device, tinkering with it and modifying with padding or tape to ensure that it continues to meet their needs without the need for external intervention. The technology needs to work for them. Users understand the importance of integrating technology into their self-identity and ability while also recognising the flipside of being controlled by it.

Prosthesis users continually reflect on the device as part of the body versus an inanimate object used as a tool (for further reflection on this see Murray, 2004). For many, the distinction is linked to function. When the device works well, enabling people to fulfil their functional goals, it is part of them, integrated into their bodily awareness. When it fails, causes pain, or limits the person in some way, it feels separate from them – a mechanical element rather than part of their body. Again, this sensation of being ‘me, but not me’, fluctuates over time and context and can impede adjustment and daily lives. This continual readjustment can be frustrating and unsettling.

The prosthetic device plays a key role in post-amputation adjustment. For some, the prosthetic device allows them to hide their missing limb, to avoid appearing ‘different’ and the potential judgements from onlookers. For others, hiding is less of a concern as long as the device provides a favourable function in comparison with others and their pre-amputated self. In recent years there has been a move towards more personalised devices, printed with favourite images of football team colours (see the work of limb-art.com for example). With the advent of 3D printing technology and advances in bionic technology, there is also a move towards more affordable and functional devices (see openbionics.com for example).

### Into the valley

Recent research has looked at the concept of the uncanny with regards to reactions towards prosthetic devices with varying levels of realistic appearance. A realistic prosthetic device falls into



**Dr Clare Uytman**  
is a Senior Lecturer at Queen

Margaret University, Edinburgh  
CUytman@qmu.ac.uk

the Uncanny Valley, producing a strong sense of discomfort and lack of affinity with the prosthetic device. Work in the 1970s by Mori (see Mori et al., 2012) suggested that prosthetists would be better aiming for less anatomically realistic devices in order to increase affinity with the device. This may go some way to explain why some individuals prefer to opt for

a device that doesn't appear realistic at all, that isn't 'pretending' to be a real limb. They understand that the device is always going to look somewhat unnatural and so reconsider their priorities for their device. Many of the contributors in my research comment that the issue is with finding a device that works well, that finding a device that both looks realistic and works well is often difficult so opting for function over appearance is preferred. As related by Tim (who had a below knee amputation 15 years previously):

You get confidence with what you are wearing. You are walking well. You are walking with assurance, jumping over stuff, the fact that it is an artificial limb is negated (...) You know? I'm saying it's kind of 'Hey, look at me! I've got this technical stuff on and it's carbon fibre and hey, isn't it smart?' And so it turns around, so rather than trying to put this cosmesis on and hide the fact that you are an amputee, you are saying 'hey bollocks, I'm an amputee and I'm O.K. I don't care cause I am as good as you. (Uytman, 2020, p.196)

More recent studies have attempted to clarify which specific elements of the device relate to the uncanny, measuring eeriness as elicited by viewing devices of varying anatomical likeness. For example, less human like, rather than more human like hands elicited a more eerie response from students who were not prosthesis users (Poliakoff et al., 2018). Similarly, both non amputee and amputee participants found the more realistic images of prosthetic hands more attractive than less realistic alternatives (Sansoni et al., 2015). However, given the importance of functionality of prosthetic devices, and the consideration of the impact of movement in the sense of eeriness reported in the Uncanny Valley, these results may have differed had the devices been viewed functioning in a 3D form rather than in 2D, static format. This finding does however provide pause for thought. Prosthetists need to consider the function, appearance and suitability of the prosthetic device for users and the variation that may be inherent in experiences of users.

As with many therapeutic relationships, consideration of the experience from a variety of angles, being open to thinking outside the box and ensuring a focus on the expectations and experiences of those who have experienced this phenomenon first-hand, offers us the best potential for meeting their needs and goals, and enabling adjustment in a positive and personally relevant way.

## Key sources

- Alexander, J. (2020). The Lag. In P. Goldschmidt, G. Haddow & F. Mazanderani (Eds.) *Uncanny Bodies* (pp. 184-193). Luna Press.
- Goldschmidt, P., Haddow, G. & Mazanderani, F. (2020) *Uncanny Bodies*. Luna Press.
- Mori, M., MacDorman, K.F. & Kageki, N. (2012). The uncanny valley [from the field]. *IEEE Robotics & Automation Magazine* 19(2), 98-100.
- Murray, C.M. (2004). An interpretative phenomenological analysis of the embodiment of artificial limbs. *Disability and Rehabilitation*, 26(16), 963-973.
- Poliakoff, E., O'Kane, S., Carefoot, O. et al. (2018). Investigating the uncanny valley for prosthetic hands. *Prosthetics and Orthotics International*, 42(1), 21-27.
- Sansoni, S., Wodehouse, A., McFadyen, A. & Buis, A. (2015). The aesthetic appeal of prosthetic limbs and the uncanny valley. *International Journal of Design*, 9(1), 67-81.
- Uytman, C. (2020) Amputation, Prosthesis Use and The Uncanny. In P. Goldschmidt, G. Haddow & F. Mazanderani (Eds.) *Uncanny Bodies* (pp. 194-203). Luna Press.



## DBT Skills Training: Enhanced™ 7-9 February 2022

# JOIN US FOR THIS BRAND NEW TRAINING EVENT

### Course Description

This 3-day advanced workshop is intended for those who have prior knowledge of DBT, and who want to enhance their learning to improve their work with their clients. It provides an in-depth look into DBT Skills within Core Mindfulness, Distress Tolerance, Emotion Regulation, and Interpersonal Effectiveness, as well as the training methods required to help patients move from skills acquisition to generalisation of skills into their natural environments. The intended purpose of the various skills and the rationale (including the evidence) for their place in the treatment are addressed. Clinical examples are used to illustrate specific skills training procedures.

As a result of this training, participants will be able to:

- Conduct DBT skills training.
- Describe the evidence, convey the rationale, teach the skills, and identify situations where Core Mindfulness, Distress Tolerance, Interpersonal Effectiveness and Emotion Regulation skills can be helpful.
- Demonstrate the following: strategies for increasing client motivation; the ability to manage questions, conversations and comments in skills training; the ability to manage interactions among skills training participants; how to solve problems that arise during skills training class.
- Employ strategies for creating an engaging skills training class where specific skills are identified to help with specific and relevant situations, where patients are motivated to engage in skills and behavioural rehearsals and where questions and activities are used to assess skills deficits.
- Conduct missing links analyses of incomplete homework assignments as well as chain analyses in the context of skills training classes.

Before participating in this course, participants must have completed any of the following:

- Dialectical Behaviour Therapy Foundational Training™
- Dialectical Behaviour Therapy Intensive Training™
- DBT Skills: Essentials™

### Trainers

#### Dr Christine Dunkley

Consultant Trainer



Christine started with the British Isles DBT Training team in 2006, and prior to that was an instigator of the Southern Health NHS trust Up to Speed training in DBT. She has provided training at the Linehan Institute in Seattle at the annual worldwide trainers meeting, and has also taught on the LI induction program for new international trainers. She is ranked in the top 10 current trainers in the world for number of intensive trainings taught, and is the most prolific trainer of intensives in the UK and Ireland.

#### Amy Gaglia Essletzbichler

Consultant Trainer



Amy is an accredited Dialectical Behaviour Therapist working as a DBT trainer and supervisor after moving from the UK to Vienna, Austria. She volunteers for the Society of DBT and is a member of the Board of Accreditation. Amy is experienced at working with a variety of populations and is trained in and has experience in delivering Family Connections and DBT-PE.

**FOR MORE INFORMATION, PLEASE GET IN TOUCH:**