**‘Being a man’ - Artist statement by Dr Shawn Sobers**

**Being introduced to the idea of Duchenne muscular dystrophy**

Before being approached to make this film I had heard of muscular dystrophy, but the name Duchenne was new to me. On reading up about the condition, and listening to the audio interviews with the 20 men who talked to the researchers, I was struck by how advances in medical science are creating new sets of questions for this emerging community to engage with, for example - how do grown men negotiate living with DMD in a system which was only previously equipped to support boys and young adults with the condition? Considerations such as the relationship between them and their parents as they become men; and the gender dynamics between them and their carers, were previously largely unchartered territory for reflective conversation, and the reality of forming loving and sexual relationships and starting a family, was beyond the lived experiences of those with DMD, and therefore not catered for by the systems that were in place to support them. Though as this research shows, it is time for the medical and support systems to adjust to these new realities. The men in this study talked about their experience with candour, humour, and in a ‘matter of fact’ way which would disarm anyone who attempted to take pity on them. This ‘matter of fact’ ethos was the starting point which informed the style of how we made the film.

**Visual style**

The illustrations in the film, beautifully drawn by Bath based artist Karen Wallis, mainly point towards the inner life and private thoughts of these men, which were so kindly shared during their interviews with the researchers David Abbott, Marcus Jepson and Jon Hastie. The video footage mainly points towards the ‘outer’ world and the veneer or so called ‘normality’. I have long been a fan of montage visual styles in all formats, and find it interesting and refreshing to collapse different art forms together, democratising perceived boundaries of ‘high’ and ‘low’ art forms – as was seen in the Pop Art movement. Although originally perceived as a purely illustration and audio piece, the inclusion of video enabled us to allow the everyday into the narrative, creating a bridge between significant personal moments which some people experience and cannot take for granted, and public moments which many of us experience and unconsciously take for granted.

Working on this film with editor Sharon Townson - (who herself has a background in health care and brought her valuable insights in building the narrative out of the 21 hours of audio interviews) – we felt it was a privilege to be allowed into these men’s personal thoughts, and tried to find a sensitive visual style to match. A visual style that was subtle enough to avoid being too literal and descriptive - allowing the men’s voices to carry the narrative, and punctuated by moments of direct illustration, bringing the men’s words to visual life. The influential Soviet filmmaker and montage film theorist [Sergei Eisenstein](http://www.brainyquote.com/quotes/quotes/s/sergeieise311274.html) presented an example of how, when describing the look of a person, how the adjectives used in the spoken word can then be translated into impressionist montage film;

*“*[*Even in a less exaggerated description, any verbal account of a person is bound to find itself employing an assortment of waterfalls, lightning rods, landscapes, birds, etc.*](http://www.brainyquote.com/quotes/quotes/s/sergeieise311274.html)*...*  
For example, “His raven-black hair…..His eyes radiating azure beams…”

Even though in far less dramatic interpretations, in this film we have attempted this same loose association between the meaning of what was spoken through the men’s voices and the visuals we overlaid - where one is not wedded to the other, but still related within an overall narrative picture of these men pragmatically negotiating the realities of growing up and living with DMD.

**The use of subtitles**

The decision to use subtitles was a difficult one, as Sharon and myself often see their (? Or is it there?) use as patronising, when they are used on television with talkers who are speaking English. We prefer instead to challenge the audience to listen carefully and to engage with the speakers in a more close and intense way, as that in itself builds the mediated relationship between the listener and speaker. It was recognised however that this film would be used in a number of different contexts, not all of which would allow for such close listening to take place. We also saw that other films made about men with DMD included subtitles, and saw it was an accepted practice within the DMD community. We knew that the importance for the men’s voices to be communicated was too important than to limit the format to only ideal screening situations, and for that reason we made two versions of the film – with and without subtitles. We hope audiences will watch the non-subtitled version, as it does give a more personal connection with the men, than when only experienced through subtitles.

Either way of watching it, we hope audiences will find this film (and wider background research) of interest. We hope it illuminates the experiences of everyday life and thoughts for these men and how it relates to their sense of identity, and their hopes and aspirations for their ever emerging future, not previously thought possible, now their lived reality.

**Film credits**

Film duration - 18 min 33 secs  
  
Thanks to all of the participants who took part in this research.   
Audio dubbing: Rich Caola  
Illustrations: Karen Wallis  
Editor and Co-Director: Sharon Townson  
Camera, Co-Director and Producer: Shawn Sobers  
Researchers: David Abbott, Marcus Jepson & John Hastie with support from the Duchenne Family Support Group

‘Men living with long-term conditions: Exploring gender and improving social care’ was a research study carried out in 2013-14 and based at the Norah Fry Research Centre, School for Policy Studies, University of Bristol. For more information about the research please contact lead researcher David Abbott at - [D.Abbott@bristol.ac.uk](mailto:D.Abbott@bristol.ac.uk)

**Reference:**

Eisenstein, S. (1949) ‘*A Dialectic Approach to Film Form’*, Film Form: Essays in Film Theory*,* New York, Harcourt Brace