

Press release
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Men with long-term conditions demand better social care

The social care sector needs to focus on gender-specific social and sexual needs when looking after men with debilitating long-term health conditions, a new study has found.

Researchers at the University of Bristol looked at the views of 20 men, aged from 21 to 33, who have Duchenne muscular dystrophy – a life-limiting neuromuscular disease which gradually causes the muscles to weaken.

The [study](#), funded by the [National Institute for Health Research \(NIHR\) School for Social Care Research \(SSCR\)](#), is being presented at the [Disability Studies Conference](#) in Lancaster on 9 September and reveals that men sometimes found that social care took no account of their male gender and they wanted more support with social activities and sexual relationships.

One participant said: “I think the actual impact of social care can be incredibly emasculating, if it is set up in such a way that it takes away your independence and your autonomy. It’s not even gender neutral, because gender’s not even in there.”

Aspects of life that the men found challenging and would welcome more support with included:

- difficulties in attracting sexual/intimate partners;
- barriers to obtaining paid work;
- questions about moving out of the family home relating to care, support and loneliness;
- restrictions on a social life linked to shortage or inflexibility of support arrangements;
- concerns about physical appearance and muscularity.

Social care staff should give cues to show that such topics are not off-limits, prompting men to feel able to discuss issues of concern.

[Professor David Abbott](#), from the Norah Fry Research Centre at the University of Bristol, said: “This group of men is just one example of people living with long-term conditions who need good quality social care. Having support to dress and wash obviously matters but what about life enhancing activities - sex, relationships, fun, risk – why are these off limits? Imagine if being the man you wanted to be meant you needed flexible and imaginative social care support. Imagine if you didn’t have this.

“The men we spoke to wanted to be treated like men, despite their increasing reliance on physical support. A headline message for the social care sector is to think about gender and the whole range of social and sexual needs men living with long-term conditions may have.”

A short film based on the research findings is available to view online:

<https://www.youtube.com/watch?v=eBovuWg-n34>

About Duchenne muscular dystrophy (DMD)

DMD is an inherited neuromuscular disease which affects males (in about 1 in every 3,500 UK births). By the age of 13, boys with DMD have generally lost the ability to walk independently. By the mid-teens there are other complications: curvature of the spine, respiratory difficulties and cardiac failure. For young people with DMD, the years between 15 and 20 are likely to mean further spinal surgery and decisions about the use of assisted ventilation for respiratory management. The mean age of death without specialised treatment was 19 but during the last few

years there have been significant improvements in the ways DMD is managed and the mean age of death is continuing to rise as more effective medical interventions emerge.

About the study

The study took place between October 2012 and April 2014. David Abbott & Dr. Marcus Jepson at Bristol worked with Dr. Jon Hastie a researcher and activist living with DMD and the study was also supported by the Duchenne Family Support Group. Twenty men with DMD were recruited to the study and participants were from a whole range of geographical locations across England including both urban and rural settings. They ranged in age from 21-33.

About the [Norah Fry Research Centre](#)

Founded in 1988, the Norah Fry Research Centre is one of the leading centres in the UK for research into disability issues. Research studies at the centre are based on a social model of disability, attempting to support disabled people and their families in identifying and tackling the barriers they face. Its principal interests are in the area of social, educational and policy-related research. The centre aims to make a positive difference to the lives of disabled children, young people and adults. It is part of the School for Policy Studies at the University of Bristol.

About the [Duchenne Family Support Group \(DFSG\)](#)

The DFSG is a national charity run by families for families affected by DMD. It provides a positive national support network of parents, their families and professionals. Since it was founded in 1987, the DFSG has helped to bring families together for mutual support, sharing of information and experience, and social activities.

About the NIHR SSCR

The NIHR School for Social Care Research was established in May 2009 to develop the evidence base for adult social care practice in England and so help to improve the quality of care and support experienced by individuals and families. SSCR is conducting and commissioning high-quality ('world class') research to produce new knowledge (including, where appropriate, reviews and syntheses of existing evidence) to inform the development of adult social care practice in England. Phase I (2009-2014) was a partnership between London School of Economics and Political Science (LSE), King's College London and the Universities of Kent, Manchester and York. Phase II (2014-2019) is a partnership between LSE and the Universities of Bristol, Kent, Manchester and York. For further information, visit the SSCR website (www.sscr.nihr.ac.uk).

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