This project is funded by the Duchenne Forum - a group of charities established to accelerate progress in the search for treatments and eventually cures for Duchenne muscular dystrophy.

Exploring the views of men with Duchenne muscular dystrophy on end-of-life care decision making

Professor David Abbott from Bristol University will investigate the views of men with Duchenne muscular dystrophy about how, when and with whom conversations about end-of-life care should take place. It has been shown that such discussions can improve quality of life in people with life-limiting conditions. The results will inform clinicians, family members and men with Duchenne muscular dystrophy about how to discuss these important but delicate issues.

What are the researchers aiming to do?

Evidence suggests that talking about end-of-life care planning can be beneficial for people with life-limiting conditions. However, this is a highly sensitive topic that is often difficult for individuals, families and clinicians to discuss. This project, which is supported by a group of multidisciplinary advisors, will consult men with Duchenne muscular dystrophy to find out how, when and with whom they would like to have these conversations.

During the course of the project, 20 men with Duchenne muscular dystrophy from across the UK will be interviewed for their views and opinions about end-of-life care discussions. The user-led organisation DMD Pathfinders will help the researchers recruit participants aged over 20 years. The interviews themselves will be divided between Professor Abbott, an experienced qualitative researcher who has worked with men with Duchenne muscular dystrophy before, and Dr Helen Prescott, a highly experienced psychologist.

The results will be collated into a short report with recommendations about how men with Duchenne muscular dystrophy would like end-of-life care discussions to take place. The report will be disseminated to clinicians and relevant health and social care professionals and should improve clinical practice in this area. The report will
also be relevant to family members and men with Duchenne muscular dystrophy and a short summary of the report will be available free from the internet.

**How will the outcomes of the research benefit patients?**

This project will increase our understanding of the views men with Duchenne muscular dystrophy have about planning end-of-life care. The report that will be produced will improve care for men with the condition as well as help facilitate discussions about this highly sensitive topic with friends, family members and the wide range of health and social professionals that support men with Duchenne muscular dystrophy.

These conversations are difficult to start and engage with, but they are believed to be beneficial to men with Duchenne muscular dystrophy and could improve quality of life for them.

**Grant information**

Project leader: Professor David Abbott
Location: Bristol University
Conditions: Duchenne muscular dystrophy
Duration: one year, starting 2014
Total project cost: £ 44,394.00
Official title: Building the Evidence Base for End of Life Decision Making for Men with Duchenne Muscular Dystrophy

**For further information**

If you would like further details about this research project, please contact:

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