

Choice, control and quality of life

welfare rights

independence

care

housing

technology

health

employment

Living longer, healthier fulfilling lives...

It's possible to achieve remarkable things with Duchenne Muscular Dystrophy (DMD)

With the right help and support we can travel around the world, gain a PhD, become a published author, graphic designer, music promoter...

THE SKY'S THE LIMIT!

We are DMD Pathfinders, a user-led organisation and our mission is to improve quality of life for teenagers and adults with DMD in the UK.



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DMD Pathfinders Impact Report 2015 -2016

Introduction

DMD Pathfinders is a user-led charity (reg. no. 1155884) which was set up in 2014 to promote choice and control and quality of life for teenagers and adults with Duchenne Muscular Dystrophy in the UK.

It campaigns for improved standards of health and social care and provides advice, guidance and support to teenagers and adults with Duchenne Muscular Dystrophy on issues such as independent living, housing, employment and welfare rights.

The aims of DMD Pathfinders are:

- I. To provide a voice for adults living with DMD.
- II. To provide a forum for adults living with DMD to share experiences, ideas and opinions in complete confidence.
- III. To provide information, advice and peer support to adults living with DMD.
- IV. To identify, promote, and develop best practice, innovative treatments and technologies for adults living with DMD.
- V. To campaign and influence treatments for adults living with DMD within health and local authorities, government, relevant professionals, disability organisations and charities.
- VI. To work with health and local authorities, government, disability organisations and charities in improving care, support and services for adults living with DMD.
- VII. To increase awareness of adults living with DMD.

About Duchenne Muscular Dystrophy

Duchenne is a fatal genetic muscle-wasting condition that affects 1 in 3500 births and currently there is no cure. There are an estimated 500 people in the UK aged over 18 with Duchenne and many more with Duchenne-like types of dystrophy. In later stages, Duchenne leads to almost total paralysis, reliance on a ventilator to breathe and a need for round-the-clock-care.

Due to advances in medical care in the last few decades we are now living well into our 20's,30's and 40's, with extensive health, care and social needs.

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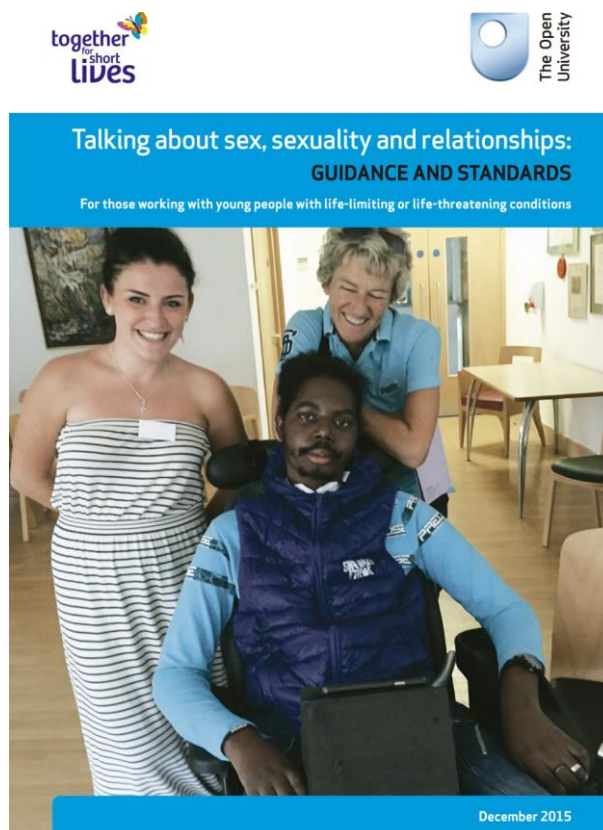
We are an unforeseen generation, since we were not expected to still be alive and as a consequence organisations and agencies that were originally created to advise and support our parents/carers, have been slow to respond to our needs.

What have we done to achieve our core aims?

I. To provide a voice for adults living with DMD.

In 2015 /2016 DMD Pathfinders has been part of the Open University Sexuality Alliance working to raise awareness of the issues of disability and sexuality among professionals/carers/parents and young people with a disability.

Mark Chapman has taken part in workshops facilitated by the Open University Sexuality Alliance in Edinburgh and London. The result has been the publication of guidance aimed toward hospice staff to support young people with life limiting conditions with sex, intimacy and relationships.



The guidance is available online: [Talking about Sex, Sexuality and Relationships: Guidance and Standards for those working with people with life limiting conditions.](#)

In November, DMD Pathfinders hosted a panel session entitled “An International Conversation with Adults with DMD” at the Action Duchenne International Conference and represented the needs of adults with DMD at a range of workshops Supported by DMD

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Pathfinders Mark Chapman, Jon Hastie, Farhan Mian, Ravi Mehta, Mithun Soul and Matt O'Sullivan led a number of workshops on subjects which had been identified in advance as of particular importance to young people and families in Transition. These included workshops on Pathways to Employment, Budgets and Brokerage, Personal Health Budgets, Personalisation and getting the life you want for yourself whilst living with DMD.



Mark Chapman & Jon Hastie opening the Action Duchenne Conference

DMD Pathfinders has provided the voice of adults in the Action Duchenne Takin' Charge programme, ensuring that this programme has delivered precisely the information, advice and guidance that young people and adults with DMD and their families find of use during Transition.

II. To provide a forum for adults living with DMD to share experiences, ideas and opinions in complete confidence.

DMD Pathfinders continues to provide an online closed Facebook group for people living with DMD to raise issues of concern to them in confidence. It has over 320 members. Through this group, DMD Pathfinders have collated evidence of the extent of need within the Adult DMD Community.

The online group provides support to adults living with Duchenne to live productive, fulfilling and independent lives. The many questions and concerns from our members have highlighted the need for information and advice in key areas and we have developed a wishlist of advice resources for us to take forward next year.

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DMD Pathfinders have invited guest bloggers to write advice and guidance on our website on key areas of interest. This has included:

- How to get to University
- Mental Health and the value of peer support
- The journey towards independent living

III To provide information, advice and peer support to adults living with DMD.

In March, DMD Pathfinders secured a Big Lottery Grant to help develop mentoring and social media skills of its volunteers and trustees.

This built on the pilot work conducted earlier in the year where members and Trustees of DMD Pathfinders contributed to the Action Duchenne Takin' Charge preparation for adulthood programme for young people with DMD 14 – 25. In July 2015, DMD Pathfinders Mithun Soul and Farhan Mian spoke about their different experiences of living as independent adults.

They both talked about the different housing options that they have managed to secure for themselves, how and why this housing option works for them and what difference it makes to their lives. One young adult with DMD told us he was very impressed with the information he got from Farhan & Mithun and appreciated the opportunity to meet up and have a chat about a range of issues including recruiting and managing PA's.



Mithun, Farhan & Aaron at the pilot mentoring session in July 2015

Two mentoring development sessions were held in Newcastle and in Birmingham at the beginning of April. At Birmingham, our members Ryan, Mithun and Aaron received

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coaching around what good mentoring means and identified how they could use their own experiences and achievements to encourage young people with Duchenne to think about their goals and aspirations for the future. They had an opportunity to put these new skills into practice at the meeting where they talked to young people and their families about the importance of planning for leaving school/college and having a clear plan as to how you are going to achieve your goals.

Ryan Worth said:

“It was a privilege to show young people with Duchenne that there is life beyond the condition and to not allow anyone to silence you. Society can be the biggest factor in disabling people such as ourselves, with help we can be integrated. We need to be put at the forefront and it can take a push from parents but it’s vital for changing attitudes, and disabled people have to be at the heart of any discussions regarding our future/policy decision. It’s an honour to be involved in such a project “



Ryan & Mithun presenting to families and young people living with DMD

DMD Pathfinders have held discussions with leading dieticians and nutritionists working with adults with DMD, and is now developing a Nutrition Guide for adults with DMD.

IV To identify, promote, and develop best practice, innovative treatments and technologies for adults living with DMD.

On 23rd March, DMD Pathfinders held an innovate event using participatory radio, supported by Radioactive 101 from the University of East London. The event enabled 7 adults with DMD to meet up in St Joseph’s Hospice Hackney, and a further 3 to take part via Skype to create a radio show. As well as coming together on the day, this involved

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members meeting up beforehand to plan and research for the show, supporting them to be creative and learn new skills and develop confidence in finding their voice and sharing ideas. DMD Pathfinders hopes to continue to develop this work as a best-practice approach to tackling the social isolation that many adults with DMD experience,

DMD Pathfinders has contributed to research studies relevant to adults with DMD, helping to recruit participants and informing research design on the project “Men living with long term conditions: exploring gender and improving social care.” This research was carried out by Prof. David Abbott at the Bristol University School of Policy Studies.

V. To campaign and influence treatments for adults living with DMD within health and local authorities, government, relevant professionals, disability organisations and charities.

Members of DMD Pathfinders have been actively supporting other Duchenne charities in their campaign to get funding for treatments for DMD. This has included lobbying for approval of Translarna by NHS England. DMD Pathfinders has also raised the need to ensure that treatments such as Translarna can benefit adults with the condition.

VI. To work with health and local authorities, government, disability organisations and charities in improving care, support and services for adults living with DMD

On July 10, Mark Chapman represented DMD Pathfinders with 11 other UK & Ireland Patient Organisation Participants at the National Workshop on DMD Clinical Trial Capacity organised on behalf of TREAT-NMD, held at the Centre for Life in Newcastle. DMD Pathfinders contributed to the discussions to ensure that initiatives to expand capacity for clinical trials took into account the need to ensure clinical trials for DMD treatments include adults. A number of DMD Patient Organisations agreed to fund additional staff posts and DMD Pathfinders continues to be linked into this work.

VII. To increase awareness of adults living with DMD.

All of the work of DMD Pathfinders on its facebook group, website, social media, attendance at conferences and lobbies has increased awareness of the needs of adults living with DMD.

The grant from the Big Lottery Fund was awarded for both mentoring and the development of social media and admin capacity within the organization. This aims to make the organization more sustainable in the future.

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The project started in March 2016 and held an initial scoping meeting with 5 adults living with DMD, who met with a social media consultant to identify the skills and competencies they aim to develop over the year long project.

Adults with DMD are increasingly seeking to contribute as volunteers to the awareness-raising work DMD Pathfinders carries out on social media, whether as guest bloggers or working behind the scenes. One example was an interview carried out by one of our volunteers with Savant Thakur, a BioMedical Researcher who is also living with Duchenne.

DMD Pathfinders members contributed to the patient advocacy of Solid Biosciences, a pharmaceutical company working in the field of DMD research, by submitting patient stories and photographs intended to give children & adults with DMD and their families a platform to share their talents, unique qualities, and challenges. The partnership with a pharmaceutical company provided a means to further the reach of DMD Pathfinders in its awareness raising efforts.

Looking to the future

With improved medical care and the reality of more people with Duchenne living into adulthood, the role of a charity for adults with Duchenne run **by** adults with Duchenne is even more crucial. DMD Pathfinders have coped well with the challenges of being a new user led organization. The focus for future work is to continue to deliver on our core aims as well as to build the skills of people involved in the organization so as to be sustainable in the future!

Financial Review

As a fledgling user-led organization, our income and expenditure has been very limited this year. Our outcomes have been met by partnering with other charities and thanks to a wealth of time and work donated by our trustees, members and volunteers. We raised over £17,000 this year and had no expenditure, which brings us closer to our development goals. DMD Pathfinders has developed a business plan for the next year which aims to increase our fundraising efforts and invest funds in further capacity-building and project management work to advance our core objectives.

Our Trustees

Our trustees as of 5 April 2015 were:

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Mark Chapman, Chair
Jon Hastie, Trustee
Robert Watson, Trustee
John Ashby, Trustee
Alan John Pockley, Trustee
Ryan Worth, Trustee
Celine Barry, Trustee
Mithun Soul, Trustee
Farhan Mian, Trustee

No changes were made to the trustee board during the 2015-16 year to which this annual report refers.

About Pathfinders

DMD Pathfinders is a charitable incorporated organisation (CIO) with an "association model" constitution, as an organisation with voting members other than its charity trustees. The constitution was agreed on 5 February 2014.

Membership of the CIO is open to anyone living with Duchenne Muscular Dystrophy who is interested in furthering its purposes, as well as people living with conditions with a similar presentation to Duchenne Muscular Dystrophy at the discretion of the trustees.

At each annual general meeting one third of the charity trustees shall retire from office. These trustee vacancies are appointed by decision of the members at the annual general meeting. Charity trustees may decide to appoint a new charity trustee at any time outside of an AGM. A person so appointed by the charity trustees shall retire at the conclusion of the next annual general meeting. There are no limits on the number of terms a trustee may serve, if reappointed by members.

Contact Us

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Declaration

The trustees declare that they have approved the trustees report above.

Signed on behalf of the charity's trustees:

A handwritten signature in black ink, appearing to read 'M Chapman'.

Name: Mark Chapman

Position: Chair of the Board of Trustees

Date: 5th December 2016