Improving psychosocial care for Duchenne muscular dystrophy: A family guide to our plans

It is possible to live a happy and fulfilling life with Duchenne muscular dystrophy (DMD) and more children and young people than ever are planning positive futures as they grow into adulthood. As well as physical needs there are established learning and psychological (or **psychosocial**) risks that children and young people with DMD experience that might benefit from specific support. These difficulties are often overlooked or misunderstood, and it can be hard to get professional assessments, support and interventions.

We are addressing this in DMD Care UK, a collaborative project that brings together the clinical and patient communities with one shared goal – to improve care for all people with DMD, no matter where they live in the UK. Duchenne Research Fund and Joining Jack have funded the key team members pictured here, for three years to carry out research and develop guidelines on best practice and assessments for psychosocial care in the UK.

The project will also keep track of the unmet need from the DMD community – looking at how many referrals and what types are requested. This information will be used to show the level of need to the NHS and make a better case to fund these kinds of posts in different centres around the UK.



Dr Chloe Geagan
paediatric clinical psychologist
Newcastle University
(3 days)



Avneet Sandhu
paediatric assistant psychologist
Newcastle University
(3 days)



Dr Linda Bouquillon
adult clinical psychologist, University College London Hospitals Trust
(5 days)



Dr Rory Conn
paediatric liaison psychiatrist
Devon Partnership Trust in Exeter
(1 day)



Dr Dot Bindman
adult neuropsychiatrist, University College London Hospitals Trust
(1 day)

DMD CARE UK
Best care for all

Posts funded by:

Duchenne Research Fund
£640,000 over 3yrs

Joiningjack.
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Examples of psychosocial risks

Mental health: depression, suicidal thoughts, low mood, anxiety, feeling unable to cope, grief

Neuro-behavioural issues: including attention deficit hyperactivity disorder (ADHD), anxiety, autism spectrum disorder (ASD), obsessive compulsive disorder (OCD), hypersensitivity

Neuro-cognition: specific learning difficulties, dyslexia (problems learning to read), dyscalculia (problems with arithmetic), dysgraphia (problems with writing)

Physical and care aspects of life with DMD: accepting and managing help required for personal care, coping with physical transitions, (e.g. stopping walking), coping with surgical procedures (e.g. spinal surgery)

Social aspects of life with DMD: living independently, being able to access a full education, employment and career, social life and relationships

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What does this mean for you now?

During this project-funded phase, our team can work directly with some people with DMD and their families – but do remember that a significant part of their time is for research.

This research will lead to a better understanding of the needs of people with DMD and their families and therefore more effective identification, support and treatment across the whole of the UK. We hope that this will reduce the impact of psychosocial risks in DMD and significantly improve quality of life.

The clinical psychologists will be part of the neuromuscular multi-disciplinary teams at Newcastle and at UCL – they will mostly see patients at those centres as well as supporting and advising their colleagues.

The psychiatrists can offer a more national approach. They hold open advice sessions for clinicians every month to help answer their questions about psychiatric support. They can also see a limited number of patients (online) from anywhere in the UK.

People need to be referred for this appointment by their neuromuscular team. It is important to remember that this is still a very limited resource, but if you or your neuromuscular team feel that a psychiatrist might be able to help, they should get in touch to discuss a referral.

For information about accessing advice and referrals, please contact Cathy Turner catherine.turner@ncl.ac.uk

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What is a clinical psychologist?

Clinical psychologists are trained to offer 'talking therapy'. In DMD Care UK, they might do this with children, young people or adults living with Duchenne and their families. Clinical psychologists are also trained in carrying out assessments of a person's cognition, including general abilities, memory and attention. A clinical psychologist is not able to prescribe medication.

What is a psychiatrist?

Psychiatrists are medically qualified doctors who have specialised in working with people with mental health problems and their families. They may also offer therapy to individuals like clinical psychologists do. However, they are more likely to be asked to see people when medication is being considered as part of a more comprehensive care package. **Our psychiatrists may recommend medications for local clinicians to prescribe, under their advice and guidance.**

Clinical psychologists and psychiatrists often work together to help families.