

Living Life to the Fullest

You are being invited to participate in a research project called Living Life to the Fullest. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Feel free to ask us if there is anything that you do not understand, or if you would like more information. Thank you for taking the time to read this Participant Information Sheet.

Parent Participant Information Sheet

What is the project's purpose?

Living Life to the Fullest is a research project that seeks to forge new understandings of the lives, hopes, desires and contributions of children and young people with 'life-limiting' or 'life-threatening' impairments (hereby LL/LTIs) and their families.

Working in partnership with children and young people with LL/LTIs and their families, as well as leading disability and arts organisations *DMD Pathfinders*, *Purple Patch Arts*, and *Good Things Foundation*, the project will be a space where disabled children and young people and their families can tell new stories of disability; their own stories.

Our culture has some problematic ideas about disability and disabled people's lives, particularly the lives of disabled children and young people with LL/LTIs. Quite often, people think that disabled children and young people live tragic, sad and unhappy lives without opportunities for play, socialising and friendships. Through engagement with narrative and the arts, this project aims to offer opportunities for disabled children and young people with LL/LTIs to speak about their lives in "new" ways: as joyful, creative, fun, challenging, but ultimately liveable, just like anyone else. This is important because knowledges about life with LL/LTIs rarely come from disabled children and young people or their families themselves.

The research will run for 3 years, beginning in April 2017 and ending in March 2020.

Please see our website see livinglifetothefullest.org

Why have I been chosen?

We want to invite parents of children and young people with LL/LTIs to participate in an online interview. We are asking you to participate because you are a parent of a disabled child.

Do I have to take part?

No, it is completely up to you whether you take part or not. Your participation in Living Life to the Fullest is entirely voluntary.

You will be asked to sign a consent form to say that you are happy to participate in Living Life to the Fullest. However, you can still change your mind and stop participating (also known as 'withdrawing'). You can withdraw at any time, and you do not even have to give a reason.

What do I have to do?

You will participate in a one-on-one interview that will take place online. You can be interviewed over Skype, on Facebook Messenger, or over email; whichever feels most comfortable to you.

A co-researcher from the Co-Researcher Collective will interview you. The Co-Researcher Collective is a group of young adults living with LL/LTI who are contributing to the running of the project.

Co-researchers are facilitated and supported by Dr Kirsty Liddiard at the University of Sheffield.

Will I be recorded, and how will the recorded media be used?

The audio recordings of your activities made during this research will be used only for analysis and for illustration in conference presentations and lectures. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

What are the possible disadvantages and risks of taking part?

We don't foresee any serious disadvantages or risks in participating in Living Life to the Fullest. However, sometimes reflecting on our lives can be upsetting or distressing, or you might be exposed to other young people's thoughts and feelings, for example, around death and dying, which might cause discomfort or be distressing to hear.

You do not have to answer every question in the interview; you have the right to say no to questions if you do not wish to answer them.

You will be in a supportive space: you can take time out whenever you wish. In addition, if you feel like you need it, post-interview support can be provided. For example, this might be in the form of a counselling session or telephone conversation with a trained counsellor – but only if you feel that this is right for you.

What will I gain from taking part?

Participating in an interview is a chance to tell your story and contribute to an important research project that aims to improve the lives of disabled young people with LL/LTI and their families.

What happens if the research project stops earlier than expected?

Although unlikely, if for any reason the research project stops earlier than expected, you will be offered a full and clear explanation as to why.

What if something goes wrong?

If you feel something has gone wrong or would like to raise an issue/complaint, you are advised to make contact with the Principle Investigator (PI) of Living Life to the Fullest, Professor Dan Goodley. You can find his contact details at the end of this document.

If you feel that your complaint has not been dealt with appropriately, you can contact the Head of Department at the School of Education at the University of Sheffield, Professor Elizabeth Wood, who will escalate the complaint through the appropriate channels:

Professor Elizabeth Wood
Head of School
The School of Education, Edgar Allen House, University of Sheffield, 241
Glossop Road, Sheffield, S10 2GW
Tel: +44 (0) 114 222 8172
Email: e.a.wood@sheffield.ac.uk

If your complaint relates to how your personal data has been handled, information about how to raise a complaint can be found in the University's Privacy Notice: <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>.

Will my taking part in this project be kept confidential?

As a participant of the research, your participation in the project will be kept strictly confidential. You **will not be identified** in any reports or publications when we write up the findings of the research. We will give you a pseudonym (e.g. a fake name). However, if you tell us something that worries us, whereby you are in danger or at serious risk, then we might have to share it with someone else; such as a professional or someone you trust. We will let you know if we plan to do this.

Your data (your interview story) will only be shared with your interviewer, and the University of Sheffield Research Team: Dan Goodley, Katherine Runswick-Cole and Kirsty Liddiard (see our details at the end).

What will happen to the results/findings of the research project?

In the third year of the project, we will be working in a variety of ways to make sure that our findings have *impact* – that they matter, and are meaningful and relevant to the lives of children and young people with LL/LTI and their families. We will be sharing what we have found – our findings, or results – in a number of different ways to ensure that people know about them.

Firstly, we will be publishing the results of the research in academic journals, magazines, newspapers and online. We might also talk about the research and its findings on television and radio, or at conferences in the UK and overseas. We also want to let politicians, policy makers, and the people who work with and for children and young people with LL/LTI (e.g. doctors, care staff, respite workers, teachers) know what we have found.

Future research: The Economic and Social Research Council, also known as the 'ESRC', funds Living Life to the Fullest. All ESRC-funded research must comply with the requirement to make all data generated by the project available via the UK Data Service, a resource funded by the ESRC to support researchers, teachers and policymakers who depend on high-quality social and economic data. Due to the nature of this research it is very likely that other researchers may find the data collected to be useful in answering future research questions. We will ask for your explicit consent for your data to be shared in this way and if you agree, we will ensure that the data collected about you is untraceable back to you before allowing others to use it. If you have any questions about this, don't hesitate to ask.

15. Who is organising and funding the research?

The Economic and Social Science Research Council (ESRC) funds living Life to the Fullest (grant reference: ES/P001041/1).

Living Life to the Fullest is a research project of the University of Sheffield. Community Research and Impact Partners to the research include Muscular Dystrophy UK Trailblazers; Purple Patch Arts; DMD Pathfinders, Together for Short Lives, and Good Things Foundation.

Who has ethically reviewed the project?

This project has been ethically approved via the School of Education's ethics review procedure. The University's Research Ethics Committee monitors the application and delivery of the University's Ethics Review Procedure across the University.

What is the legal basis for processing my personal data?

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University's Privacy Notice

<https://www.sheffield.ac.uk/govern/data-protection/privacy/general>.

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

17. Contact for further information

If you have any questions about the study, please contact either:

Dr. Kirsty Liddiard
Research Fellow
The School of Education, Edgar Allen
House, University of Sheffield, 241 Glossop
Road, Sheffield, S10 2GW
Email: k.liddiard@sheffield.ac.uk
Tel: (+44) (0)114 222 8111



Professor Katherine Runswick-Cole
Professor of Critical Disability Studies &
Psychology
The School of Education, Edgar Allen House,
University of Sheffield, 241 Glossop Road,
Sheffield, S10 2GW
Email: K.Runswick-Cole@mmu.ac.uk
Phone: 0114 222 8101

Alternatively, you can contact the research's Principle Investigator,
Professor Dan Goodley:

Chair in Education and Director of Research
The School of Education, Edgar Allen House,
University of Sheffield, 241 Glossop Road,
Sheffield, S10 2GW
Email: d.goodley@sheffield.ac.uk
Phone: +44 (0) 114 222 8185



You will be given a copy of this information sheet and a signed consent form to keep.

**Thank you for taking the time to read about the Living
Life to the Fullest project 😊**