

Living Life to the Fullest – The Co-Researcher Collective

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In association with Purple Patch Arts, Good Things Foundation, DMD Pathfinders, iHuman, University of Sheffield, and with thanks to the Economic and Social Research Council ESRC).

What is the Living Life to the Fullest Project?

The Living Life to the Fullest Project is a research project which seems to forge new understandings of the lives, hopes, desires and contributions of children and young people labelled with life limiting or life threatening impairments.

Why is researching the lives of disabled young people important?

Research is important because we need to evidence, quantify and qualify a certain topic, subject or issue in order to build upon and better understand it. Research is the cornerstone of all society, it's what we use to build our services and our actions upon so it's really important that we research young disabled people and our needs, wishes, views and our lives and our contribution to society.

Living Life to the Fullest is co-led by the Co-Researcher Collective, a group of young women with what are known as life limiting and life threatening impairments.

The Living Life to the Fullest Research Collective does exactly what it says on the tin. We are looking at the lives of young disabled people to see how and if they are living them fully.

How was the Co-Researcher Collective established?

I am a part of Living Life to the Fullest as a lead Co-Researcher as part of the Co-Researcher Collective, which means I'm part of the research management team. When I joined Living Life to the Fullest I was tasked with creating a Co-Researcher Collective of young people, and I am really proud to say we've achieved that. We have some fantastic young disabled people as part of our research team. We are here to be integral to the design, the collecting of data, and the writing up of that data and the writing up of the whole research project, but also in disseminating that.

In the Co-Researcher Collective are: Emma Vogelmann is a Law graduate, activist and writer. Sally Whitney has been living with life threatening illnesses since she was 17 but her life is made much fuller by her assistance dog Canine Partner Ethan. Carrie Aimes is a 29 year old full time wheelchair user, blogger and writer. Lucy Watts MBE is a proud young disabled woman with a passion for the great outdoors, for writing and photography, who dedicates her time to making a difference for others and lives life to the fullest with support from her Assistance Dog Molly. Katy Evans is

a disabled young woman. She is a Disability Studies graduate and now works with a number of third sector organisations. Katy is rarely without her Canine Partner Folly, who is her assistance dog and 24/7 comedian! Ruth Spurr is a disabled young woman and blogger whose blog is entitled Ruth's Bucket List: A Spoonie's Journey Through Life. In this short film Co-Researchers share their experiences of being and becoming researchers.

Emma Vogelmann

Hi, my name is Emma Vogelmann and I'm one of the Co-Researchers on the wonderful Living Life to the Fullest project. And I joined the project because as a young disabled person with a life limiting condition I've answered loads of questionnaires, loads of surveys about my condition and my life but I've never been asked how I feel about my life and how I feel about my future, and if my life limiting condition impacts how I think and feel in any way. So I thought this project was a great opportunity to really understand what's on the minds of young people with these conditions and what their hopes and ambitions are, and that hopefully we'll leave behind a legacy that will show that we are just like everyone else, we have our insecurities, we have our ambitions, and this project will serve as a record of the amazing things that we achieve and all the things that we hope to achieve. So hopefully you all enjoy our research as much as we had fun conducting it.

Carrie Aimes

To me, Living Life to the Fullest means setting personal, meaningful, motivational goals and focusing my time and energy into achieving them. I feel privileged to have been invited to participate with the Living Life to the Fullest Project as a Co-Researcher. I aim to play an active role and to contribute effectively to this worthwhile research project since I consider it to be so significant and relevant to me and my peers in the LL/LTI community. Together we may seek to improve the lives of young disabled people with life limiting conditions. I hope to acquire valuable new skills and experiences whilst also building my self confidence, which is something I really struggle with. The aim of the project is to use the Arts to understand the lives of young disabled people living with life limiting conditions by demonstrating that our experiences, skills, knowledge and talents are of value to the community. Having studied Art at undergraduate level it will be great to put these to good use and impart my expertise for such a purpose. It is, I feel, essential to recognise and raise awareness of the lives of young disabled people.

Ruth Spurr

I want our voice to be heard and for people to know that we have hopes and dreams just like everyone else. Our lives are just as much fulfilling and joyful and happy and fun as anyone else's lives. We have challenges and things are difficult at times and our lives will be cut short, and some definitely will be shorter. I live myself with a life threatening illness and any time, you know your life can be cut short - just like that. But actually it makes me want to live my life to the full just as much more, it makes

me appreciate every opportunity, every moment I have and I grasp it with both hands. And I want this project to show that we have hope, we have dreams. Why can't we dream? We should dream big and we should know that our lives are worth something and we are going to make a difference in our lives no matter how old we get to and how our illnesses progress.

Sally Whitney

It gives me a purpose and a belief that both I and others with life limiting or life threatening impairments have important relevant things to say and add to our society, as well as to the discussion surrounding the understanding of disability in general. Research is also a way to commit with others in similar circumstances and gain a unique perspective into what their world is like. I found the research both illuminating and empowering as I hear the narratives that challenge the current understanding of young adulthood and disability and stories that echo and reinforce my own experience. Being a young disabled adult can be lonely and the converging of voices is a powerful step away from that loneliness.

Co-producing stories

Who is in a better position to draw out and articulate the desires, hardships and experiences of young people with life limiting or life threatening impairments than us and the young adults we are collecting data from? Not only is the data we collect more authentic and first hand but it allows a further insight into living as a young disabled person by asking questions not only about the difficulties but about their lives as a whole. A life with a life limiting or life threatening illness may be different from those without such conditions but it can be equally full.

Identifying barriers, encountering tragedy to influence the world.

The project identifies the barriers that young disabled people face and the hardships and disruption to their lives that disability incurs. However, more importantly the project sheds light on the fact that young disabled people often have incredible aspirations and truly full lives. People need to know that living life with a life limiting or life threatening impairment doesn't solely turn someone's life story into a tragedy. The young people we have worked with have been able to create different ways of accessing and influencing the world around them. Their hopes and ambitions are just as valid and important as anyone else's.

Katy Evans

The thing that I like most about the Living Life to the Fullest Project is the fact that all the Co-Researchers have personal experience of disability, which I believe adds authenticity to the research. It's also been great to work in a team with like-minded people and in a short space of time I've already learnt a lot from them.

Digging deep through active involvement

I'm really excited about being a Co-Researcher on this project because I think it's given the opportunity to dig deeper into things society sometimes struggle to acknowledge. I have always enjoyed research and this is my first experience of being actively involved in undertaking research.

Lucy Watts MBE

Living Life to the Fullest is a vital project looking at young disabled people like me and our lives, hopes, dreams and ambitions as well as our contributions to society. It's so important that we as young disabled people are better understood and supported. Many of us with life limiting and life threatening conditions were not expected to survive childhood, and society hasn't quite caught up with the fact that we're now living into young adulthood and beyond. They also don't seem to understand that we want to live our lives to the full, we have lives to lead, things to do, dreams to chase, goals to achieve, and society needs to support us in doing that. We may be disabled and have a life limiting condition but that doesn't mean we can't contribute to society and it doesn't mean we can't live good lives. I'm delighted to be a part of Living Life to the Fullest, this ground breaking project which involves young people in the project and not just as a subject but as part of the research management team.

Thank you.

With thanks to Purple Patch Art, Good Things Foundation, DMD Pathfinders, iHuman, University of Sheffield, and the Economic and Social Research Council (ESRC).