

# New research finds that young people newly diagnosed with MS are not getting the support they need

Submitted by: Kin Communications2

Monday, 23 April 2018

---

New research finds that young people newly diagnosed with MS are not getting the support they need

- Over 70% of people with MS experience symptoms before the age of 20
- 75% of young people with MS feel 'confused' by the information they found
- Young people with a relative with MS describe themselves as feeling 'scared' and 'powerless'

Ahead of MS Awareness Week, the MS Trust has 40 young people, who are either directly affected by MS or who have a parent with MS, available to talk to the media with the aim of raising awareness, and ensuring no young person feels like they have to face MS alone.

Every week, around 100 people are diagnosed with multiple sclerosis (MS) in the UK. Understanding MS is hard enough as an adult, but for the increasing numbers of young people affected by MS, it can be huge challenge.

This MS Awareness Week (23-29th April), the MS Trust is highlighting the impact MS can have on young people.

New research has found that increasing numbers of young people are being diagnosed with MS, with almost three quarters (70%) experiencing symptoms before the age of 20. These symptoms can range from fatigue to vision problems and intense pain. However, the survey showed that over three quarters (75%) of young people with MS feel 'confused and scared' by much of the information they've found about the condition, and 'frustrated and alienated' that so much of it was 'geared towards older people.'

Case studies from across the UK spoke about the challenges they faced dealing with an MS diagnosis at a young age.

A common thread throughout was one of loneliness: 'Knowing that someone my age was going through it would've helped me a great deal because my loneliness ate away at me for years.'

Another strong theme was that there is a lack of engaging and accessible information to help young people understand MS, both directly and when it impacts someone close to them: 'There's very little help or support for the younger generation dealing with MS.'

To help change this, the MS Trust is launching a new YouTube channel during MS Awareness Week, called MSTV. The channel will feature a range of different videos about MS, and star young people who are affected by MS in some way. The aim is to help young people get to grips with the condition, whether they have it, or are related to someone who does.

Since 90% of 12-15 year olds use YouTube, and the average person spends 40 minutes a day on YouTube, the project aims to get the right information to the people who need it most.

To donate £5 to the MS Trust text MSTV18 £5 to 70070  
ENDS

Notes to Editors:

For additional information, please contact [jack@kincomms.com](mailto:jack@kincomms.com) or [tom@kincomms.com](mailto:tom@kincomms.com) or call on 020 3958 7085

Additional case studies are available for comment or interview and the research in full is available on request.

A video interview can be found here (<https://www.youtube.com/watch?v=Pv8psFnccGc&feature=youtu.be>)