MS Trust School Awareness Pack

Multiple Sclerosis Trust

MS

Reg. Charity No. 1088353

To encourage awareness of MS within the school environment

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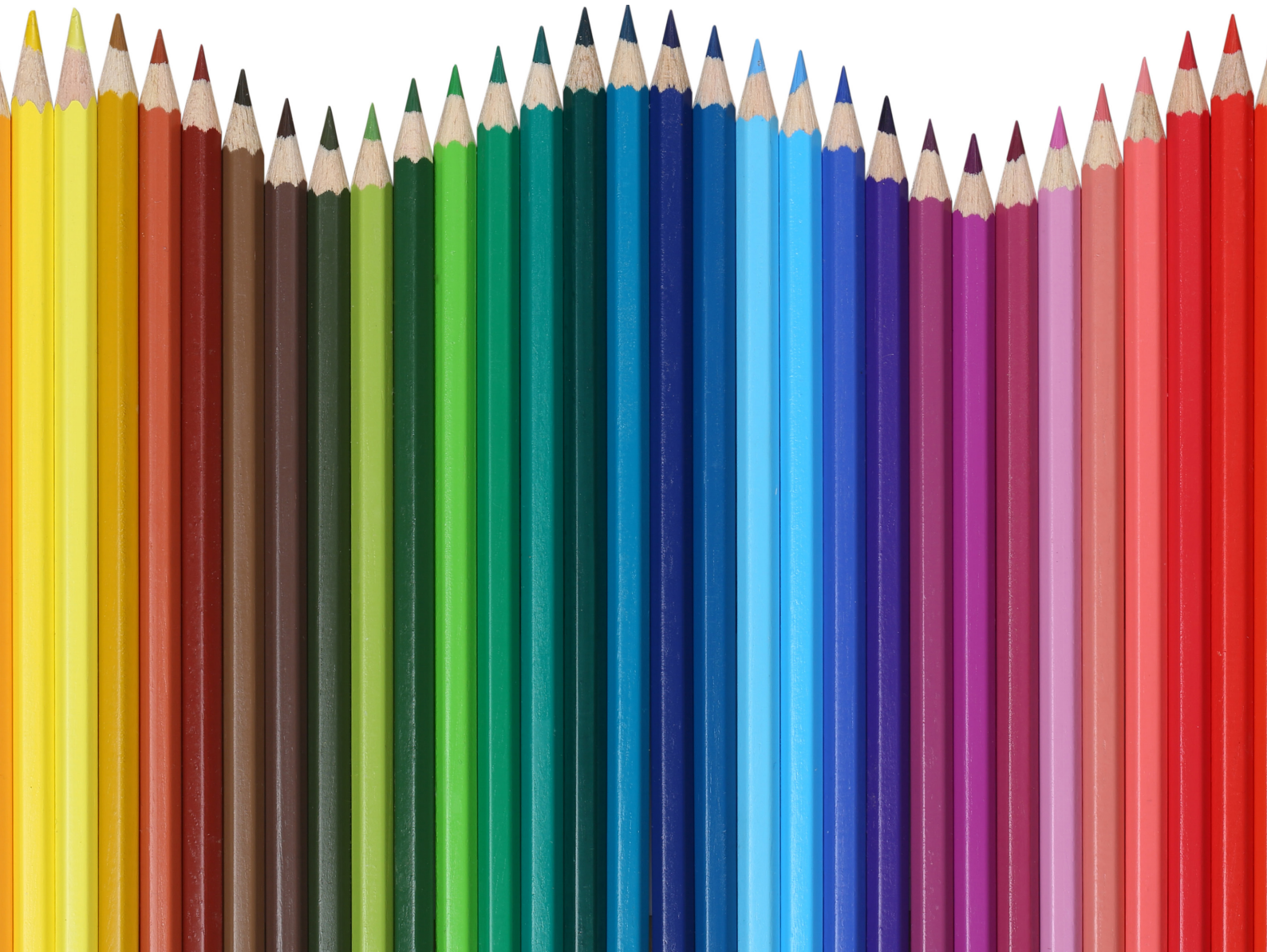
Introduction

What is MS?

MS is a lifelong disease in which the body's own immune system, which should target invading infection, instead targets the coating of nerve cells (myelin) in the central nervous system (the brain and spinal cord). This results in nerve messages to the rest of the body becoming interrupted and blocked which in turn results in devastating symptoms such as intense fatigue, numbness, pain, visual disturbance, problems with thinking, spasticity, incontinence, depression and loss of mobility.

Who is the MS Trust?

The MS Trust is a UK charity which believes that no-one should have to manage MS alone. We provide trusted information and support to help people who are living with MS now: we train and educate MS health professionals to offer the best care and we fund MS nurses in the areas of greatest need.



Children with MS

It's only recently that MS has begun to be diagnosed in children – it was thought to be an ***'adult'*** disease, and childhood symptoms were often attributed to other conditions or ignored altogether. It's now increasingly understood that MS can strike at any age. Of the **110,000** people living with MS in the UK today, it's estimated that around **5%** experienced their first symptoms before they were **16**.

Children can be given medicines to try to reduce the impact and progression of the disease but the administration can be uncomfortable, involving injection, infusion or swallowing tablets; and side-effects can be distressing and painful. Some symptoms, such as problems walking, cognitive problems and difficulties with speech and swallowing, can be embarrassing and make school life tough.

Children living with MS in the family

MS is an unpredictable disease, so children living with MS in the family don't know what they are to encounter from one day to the next. It can be hard to live a normal life. Many act as young carers for their parents and the weight of this responsibility can cause stress, tiredness, restricted social time and poor performance in school. It is not always possible for these children to express their own feelings and many do not know where to turn for support.

"The MS Trust has been a great source of learning. They do a huge amount for people with MS"
Emma

How can you help young people understand life with MS?

This schools awareness pack has been designed to encourage awareness of MS and the MS Trust with teachers, staff and, ultimately, pupils. Perhaps you would like to share with your school your own experiences of MS and help to raise the profile of MS within your local community?

Teacher with MS raising awareness of her condition at school

MS Trust supporter and teacher, Jenna Chudasama delivered an assembly about her own MS experience and explains the importance of raising awareness of MS in our schools.

Jenna Chudasama

"I was grateful to be given the chance to deliver assemblies at Sir Jonathan North College, the school that I teach at, to explain what it is like to live with an invisible condition.

It was a daunting experience at first as I did not know how my students would react. And, to be honest, I remember questioning my decision when, despite showing a small group of students an MRI scan and explaining how lesions work, someone still said that I looked fine and healthy. However, I was eventually able to help my students understand a little more about the condition by simplifying the terminology, using a lot of my personal experience and the experience of people in the public eye, such as the athlete, Kadeena Cox. Interestingly, some of my older students came to tell me that they know someone in their family or a family friend that also lives with the condition and I hope that I was able to offer additional support to them.

I wish I could confidently say that every student in my school understands the complexities of MS, but I am sure a few still struggle to understand that MS can affect people in so many different ways. Having said that, I do believe that students have a greater understanding that illnesses can be invisible. I also hope that they have been encouraged to open up about illnesses in general, similar to how their English teacher has, to remove the stigma so often attached to being ***'different'****.*

I strongly believe that it's important to raise awareness of invisible conditions, such as MS, in schools as students may have parents or relatives that live with something similar and it can allow them to access student-friendly information to support what they already know. Some of our students may also be diagnosed with MS and so I wanted to be a positive example for them to remember: I live with MS, but my life is my own. I have no regrets about opening up to my school and I hope that I have inspired others to live their life to the full, no matter what challenges they are faced with."

Fundraising and raising awareness of her mum's MS at school

When 11-year-old Alex's mum was diagnosed with MS she didn't know much about it and felt very worried. Since then Alex has learned a lot about MS and so, when MS Awareness Week came around, she wanted to help others understand more about the condition. Here Alex explains how she raised awareness and funds at her school.

"My name is Alex and I first heard about MS when my mum got diagnosed in 2015. It was scary to think that Mum had a disease that could not be cured. I didn't know much about it at first, I just knew that my mum was always a bit clumsy. At first she didn't want anyone to know about it and I sometimes got upset at school and I had no one to talk to. Mum suffered her first big relapse. I was worried, thinking the worst, but as she got better she decided to tell people and now I don't feel as alone in dealing with things. Mum had got some books from the MS Trust and I read them and this taught me that MS is not as bad as I thought it was.

When it was the MS Awareness Week I wanted to get involved and tell people and raise awareness of the disease, also to show that my mum is still the same person. I spoke to my head teacher and asked her if the school could do something to raise money for the charity. We arranged that everyone in the school would wear blue and bring a donation.

At our weekly assembly of the full school I told everyone what MS is and how it can affect people. First of all I asked two pupils to join me on stage. I made one of them kneel down so that their legs got a bit numb. I then presented a PowerPoint that I had made informing people about MS. Then the pupil who was kneeling down I asked to stand up, they stumbled and I informed the school that this is what it is like for people living with MS.

The other pupil then put on ski gloves (which are very bulky) and I asked them to tie their shoelaces. They struggled with this and were unable to manage the task, again showing what it can feel like. My dad had also given me two pieces of electrical cable to represent a spinal cord. One of them was damaged and I explained that this was like a spinal cord in a person with MS, and that the electrical signals don't get received as quickly. I feel really happy that I can now talk to my friends about my mum and they understand if she is having a lie down when they come to visit. I'm moving to high school after the summer and I hope that I might be able to do this again there in the future."

Alex

We can provide you with everything you need to raise awareness at school

MSTV

MSTV is here to help young people get to grips with MS. **MSTV** is a dedicated **YouTube** channel featuring videos on all aspects of life with MS for young people. Our young MS reporters discuss MS symptoms, get involved in fundraising, and help explain what it feels like to have MS in the family, in a lively and accessible way. We have put together a suggested playlist of films from this channel that you might like to share to help explain MS and raise awareness.

Visit **mstrust.org.uk/schoolstv**

Kids' Guide to MS

Written for **6-10 year olds**. Fully illustrated in bright colours with engaging characters, this Kids' Guide is a great resource for talking to children about MS. This booklet also includes examples and things children can try to help them understand what it feels likes to have MS, for example – hands feeling clumsy: put on a pair of boxing gloves and try to turn the pages of a comic. Can you turn one page at a time? Do you find it difficult?

Hold an information stand

If you would like to take your awareness raising further and maybe hold an information stand or even organise a fundraising event we can provide you with more resources, including:

- **Balloons**
- **Stickers**
- **Collection Boxes**
- **Flags**
- **Sponsorship Forms**
- **Posters**
- **T-shirts**
- **Banners**

Run a learning activity

Just like Alex did at her school, you could help people understand what it feels like to have one or more MS symptoms. Here are some ideas to get you started.

MS Hug

- Use a stretchy headband around the chest or torso to give an uncomfortable but safe demonstration of the tight, painful squeeze that people with MS sometimes get. It sounds friendly, but imagine not being able to get rid of that feeling (be careful not to squeeze people too long or too tightly in your demonstration!).

Odd skin sensations

- Pour fizzy water into a bowl for your friends to dip their hands in. How does that feel? Would you cope with that prickling sensation all day? Would it make it harder to get to sleep or concentrate at school?

Vision problems

- Smear Vaseline on the lenses of a pair of glasses or swimming goggles. How does that affect what you can see? Would you feel confident driving or riding a bike? Would you be able to play sport?

Balance and mobility issues

- Try walking, running or balancing activities with a single ankle weight wrapped around one leg or wrist. Once you get used to it, switch it to the other side.
- How about putting pebbles or marbles in one shoe. How quickly can you walk now? Look at the twist that puts in your back, can you imagine how that feels after a long time?
- Spin around on the spot 5 times, then try and walk in a straight line. Feeling dizzy?

Bladder issues

- Block up the spout of a mini-watering can. Modify another with random holes to spray out or leak around the handle. Do we take 'just going to the loo' for granted?

"I knew nothing about multiple sclerosis before we did this project, and all the different games and exercises helped me learn a lot" Oscar

Speech issues

- Finding the right word can be tricky for some people with MS. Try to describe an object to another person without mentioning its name. It's harder than it sounds.
- Can you recite a tongue-twister with a gum shield in? How easy is it to understand what someone is saying?

Cognition issues

- Set up random objects under a tablecloth, and give people just 30 seconds to memorise them and write a list. Try distracting them by tickling them with a feather or holding an ice cube on their neck. Is that harder to concentrate?

Numbness and dexterity problems

- Try to tie your shoelaces or butter your bread with bulky ski gloves on. How frustrating must that be to do every day? What equipment could be helpful?

Fundraising

Without the support from people in local communities choosing to fundraise for us we would not be able to continue our work.By organising a fundraising event in your school you will be helping the MS Trust to make a difference for people living with MS today.

"I want to help spread awareness and help people to understand MS in more detail whilst raising money for the MS Trust. I also enjoy participating in charity events at school because it is fun and brings everyone together" Deon

Organise a cake sale, everyone loves cake! Ask pupils and staff to donate cakes, or why not sell cakes that you have made in a cooking lesson? Or even a Bake Off competition!

Organise a coffee morning at school and ask people to donate the cost of their cuppa (coffee or tea!) to the MS Trust.

Ask pupils and staff at school to dress in blue for the day for a donation of £1.

Sponsored silence – how long can your pupils be silent for?

Give up a few hours of your time on a Saturday and pack bags for customers in local supermarkets in return for donations.

Think of a challenge – swimming so many lengths or running so many miles in a length of time.

Organise a read-a-thon and see how many books pupils/friends can read during MS Awareness Week or extend it to a whole month.

Organise a charity concert or put on a school play and get everyone involved. Ask for donations instead of entry fees.

How about holding a quiz? We can provide the questions, you just need the teams and the venue!

Examples of how your fundraising can help

£10

£10 covers the cost of sending our kids' and parents' guides to a family affected by MS

£100

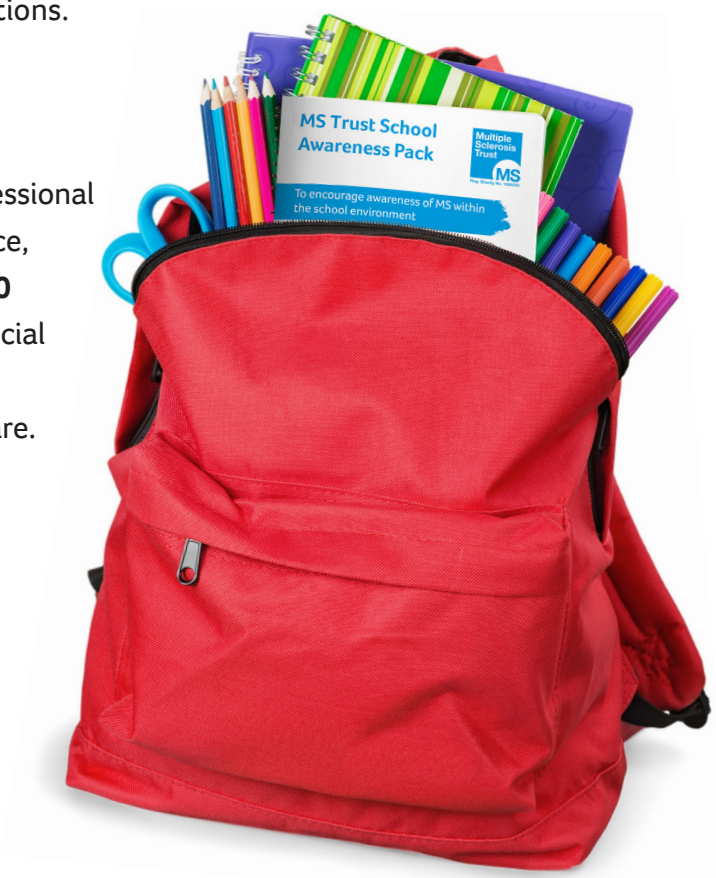
£100 can enable us to provide Making Sense of MS to the **100** people diagnosed with MS in one week.

£300

£300 can pay for our information team to respond to **20** in-depth personal enquiries to help individuals with MS take control, understand their symptoms and learn about treatment options.

£750

£750 could fund a health professional to attend our annual conference, which brings together over **300** multidisciplinary health and social care professionals who share a commitment to improve MS care.



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