



Unit 1, Maida Vale Business Centre  
Maida Vale Road  
Cheltenham  
Glos. GL53 7ER  
Tel: +44 (0) 242 261332  
Mobile: +44 (0) 7774 465712  
[www.edsociety.co.uk](http://www.edsociety.co.uk)  
Email: [info@edsociety.co.uk](mailto:info@edsociety.co.uk)

Hello,

We hope that you are all well and are managing to cope with the changes affecting all our daily lives as a result of the coronavirus. We understand that many of you are caring for children with Ectodermal Dysplasia, and this will be an extremely worrying time.

Many of us will be trying to figure out a new way of life. Parents are now taking on the task of home schooling as well as trying to do their own job, the vulnerable and the elderly are having to self-isolate and all of us are practising social distancing.

We send this email as we want you all to know that The ED Society is still here to support you, and we want to share the information we have so far about the Covid-19 situation.

Due to the current situation, our office working hours will differ, but we will be trying our best to continue providing our services and support from home too.

We'll keep our website and social media channels up to date as the situation develops. Diana is available on her mobile **07774 465712**. Please do not worry, message us or call Diana if you wish to chat things through.

We would like to thank everyone who has been getting involved on Facebook, sharing their ideas, advice and tips on how we can all get through these uncertain times.

Danielle has shared some school ideas on our Facebook page, please do not hesitate and help by posting yours too. We are #StrongerTogether, so let's stay connected.

There will be a dedicated page for all Coronavirus related information on the website to address some of your concerns. [www.edsociety.co.uk/ectodermal-dysplasia-society-home/coronavirus-and-ed/](http://www.edsociety.co.uk/ectodermal-dysplasia-society-home/coronavirus-and-ed/)

Please do encourage friends and family to sign up to our mailings to help keep up to date with all the most important news and information for families affected by ED.

We know this is a hard time for everyone, but we would still be grateful to receive your support back. Whether by receiving your donations, or signing up to easy fundraising (<https://www.easyfundraising.org.uk/> or download the app) to raise free donations from all your online shopping – which we will mostly be doing for the foreseeable future.

### **[Government guidelines on educational provision](#)**

As of Friday 20th March, all schools have closed down and no return date is known. Schools will remain open for exceptions for children of key workers, vulnerable children with social workers and children with education, health, care plan (EHCP), for which the government has now published guidance.

## **Supporting a normal lifestyle**

Ectodermal Dysplasia Society (Registered Charity No. 1089135). Disclaimer: Any views or opinions are made by the author in good faith. No liability whatsoever is accepted by the author or the Ectodermal Dysplasia Society. Recipients should make their own additional enquiries of medical and other relevant authorities before acting on these views. The use of a product name does not constitute a recommendation or endorsement by the author or the Society.

In the guidance it states that schools are being asked to remain open to provide care for a limited number of children - children who are vulnerable and children whose parents are critical to the Covid-19 response and cannot be safely cared for at home.

Vulnerable children include children who are supported by social care, those with safeguarding and welfare needs, including child in need plans, on child protection plans, 'looked after' children, young carers, disabled children and those with EHC plans.

We know that there will be a widespread concern among all our families, as children affected Ectodermal Dysplasia are placed in the vulnerable category for the coronavirus. Not only this, we know many children have EHC plans in place and have further medical conditions.

Children may find changes in their usual school environment, staffing or routine difficult to cope with. Understandably, parents do not want to put their children at risk by forcing them to attend school. The guidance states **“that if it is at all possible for children to be at home, then they should be and if a child needs specialist support, is vulnerable or has a parent who is a critical worker, then educational provision will be available for them.”**

Please continue to check our website along with the <https://www.gov.uk/coronavirus> website for daily updates. We will keep you as up to date as we can.

Take care and stay safe,

**The ED Society Team**