# Symptoms Questionnaire

This questionnaire has been designed to enable the ED Society to obtain as much information as possible regarding the symptoms you experience and how we may be able to help you. We will use this information when helping our families

* obtain the best care for their children in schools by writing a School Care Plan and assisting the school in understanding more about Ectodermal Dysplasia
* to apply for Government benefits such as DLA, PIP and Blue Badges, to write Appeal letters and attend tribunals with the family (UK only)

Please complete the following questions as fully as possible. If we have not left enough room for your answers, please use a separate sheet.

Please note these questions cover all syndromes of the many different types of Ectodermal Dysplasia, therefore, not all questions will be applicable to you or your child.

All information provided in this document will be completely confidential and will not be shared with any third party without your express permission.

## Personal Details

### Name of person with ED: Click or tap here to enter text.

### Address: Click or tap here to enter text.

### Male/Female: Click or tap here to enter text.

### Date of Birth: Click or tap here to enter text.

### Date completed: Click or tap here to enter text.

### Telephone Number: Click or tap here to enter text.

### Email Address: Click or tap here to enter text.

### Your name and relationship to person with ED: Click or tap here to enter text.

## General Patient Information

### Has a specific diagnosis for of Ectodermal Dysplasia been made? Yes [ ]  No [ ]

### If so, what type of Ectodermal Dysplasia has been diagnosed?

### Click or tap here to enter text.

Who made the diagnosis? Choose a Professional

If someone else, please state: Click or tap here to enter text.

## Teeth

### How many teeth do you have?

Adult Upper jaw - Choose a number

 Lower jaw - Choose a number

Baby Upper jaw - Choose a number

 Lower jaw - Choose a number

### Please use the picture on the following page to state which of the top and bottom four teeth are pointed? Please enter the numbers or letters

Adult Upper jaw left - Click or tap here to enter text.

 Upper jaw right - Click or tap here to enter text.

 Lower jaw left - Click or tap here to enter text.

 Upper jaw right - Click or tap here to enter text.

Baby Upper jaw left - Click or tap here to enter text.

 Upper jaw right - Click or tap here to enter text.

 Lower jaw - Click or tap here to enter text.

 Upper jaw right - Click or tap here to enter text.

###   **Adult Teeth Baby Teeth**

 Upper Jaw Upper Jaw





###

###  Lower Jaw Lower Jaw

### Using the above pictures please state which teeth are missing? Please enter the numbers or letters

Adult Upper jaw left - Click or tap here to enter text.

 Upper jaw right - Click or tap here to enter text.

 Lower jaw left - Click or tap here to enter text.

 Upper jaw right - Click or tap here to enter text.

Baby Upper jaw left - Click or tap here to enter text.

 Upper jaw right - Click or tap here to enter text.

 Lower jaw - Click or tap here to enter text.

 Upper jaw right - Click or tap here to enter text.

### Do you have dental implants? Yes [ ]  No [ ]

### Did your Dentist have difficulty placing the implants? Yes [ ]  No [ ]

### Were your implants successful? Yes [ ]  No [ ]

### If no, please explain what happened Click or tap here to enter text.

### Did you have bone grafting? Yes [ ]  No [ ]

### Is your jaw bone density very hard? Yes [ ]  No [ ]

### Do you wear dentures? Yes [ ]  No [ ]

### Did you have a cleft palate? Yes [ ]  No [ ]

### Did you have a cleft lip? Yes [ ]  No [ ]

### Do you have weak enamel? Yes [ ]  No [ ]

### Do you have enamel discolouration? Yes [ ]  No [ ]

### Do you suffer with recurrent mouth ulcers? Yes [ ]  No [ ]

### Do you have delayed speech problems? Yes [ ]  No [ ]

### Do you have speech problems? Yes [ ]  No [ ]

### If yes, what speech problems do you have? Click or tap here to enter text.

### Do you have any other teeth/mouth problems? Yes [ ]  No [ ]

### If yes, what are they? Click or tap here to enter text.

### Are you currently having any dental work? Yes [ ]  No [ ]

### If yes, please explain? Click or tap here to enter text.

## Ears

### Do you have nerve or other deafness? Yes [ ]  No [ ]

### Do you wear hearing aids? Yes [ ]  No [ ]

### Do you have sensitive hearing? Yes [ ]  No [ ]

### Do you have impacted ear wax? Yes [ ]  No [ ]

### Is your ear canal narrow or misshapen? Narrow [ ]  Misshapen [ ]  Normal [ ]

### Do you have grommets? Yes [ ]  No [ ]

### Do you have recurrent ear infections? Yes [ ]  No [ ]

### Do you have any other ear problems? Yes [ ]  No [ ]

### If yes, what are they? Click or tap here to enter text.

## Nose

### Have you had nasal reconstruction? Yes [ ]  No [ ]

### If yes, when? Click or tap here to enter text.

### Do you suffer frequent colds? Yes [ ]  No [ ]

### Do you suffer recurrent nosebleeds? Yes [ ]  No [ ]

### Are your nosebleeds frequent [ ]  occasional [ ]  severe [ ]  mild [ ]

### Do you have nosebleeds during the night [ ]  during the day [ ]  both [ ]

### Do you suffer recurrent chest infections? Yes [ ]  No [ ]

### Do you suffer thick nasal mucous? Yes [ ]  No [ ]

### Do you suffer nasal crusting? Yes [ ]  No [ ]

### Do you have bad smelling nasal discharge? Yes [ ]  No [ ]

### Do you suffer asthma? Yes [ ]  No [ ]

### Have you had your adenoids removed? Yes [ ]  No [ ]

### Do you have any other nose problems? Yes [ ]  No [ ]

### If yes, what are they? Click or tap here to enter text.

## Throat

### Do you have large amounts of phlegm? Yes [ ]  No [ ]

### Do you have a lack of saliva? Yes [ ]  No [ ]

### Do you choke easily? Yes [ ]  No [ ]

### Do you have swallowing difficulty? Yes [ ]  No [ ]

### Do you have gastroesophageal reflux? Yes [ ]  No [ ]

### Do you have recurrent choking? Yes [ ]  No [ ]

### Do you have a hoarse voice? Yes [ ]  No [ ]

### Have you had your tonsils out? Yes [ ]  No [ ]

### Do you have any other throat problems? Yes [ ]  No [ ]

### If yes, what are they? Click or tap here to enter text.

## Respiratory

### Do you aspirate (food/water/etc., enters the airway when swallowing causing coughing/choking)?

###  Yes [ ]  No [ ]

### Do you have silent aspiration (food/water/etc., enters the airway when swallowing without coughing/choking)?

###  Yes [ ]  No [ ]

### Do you use a humidifier? Yes [ ]  No [ ]

## Sleep

### Do you bedwet? Yes [ ]  No [ ]

### Do you have difficulty getting to sleep? Yes [ ]  No [ ]

### Do you have difficulty waking up? Yes [ ]  No [ ]

### Do you wake regularly during the night? Yes [ ]  No [ ]

### What causes you to wake regularly? Click or tap here to enter text.

## Nails

### Please describe your finger nails Weak [ ]  Ridged [ ]  Brittle [ ]  Flaky [ ]  Thick [ ]  Small [ ]  Slow Growing [ ]  Flat [ ]

###  Spoon shaped [ ]  Normal [ ]  N/A [ ]

### Please describe your toe nails Weak [ ]  Ridged [ ]  Brittle [ ]  Flaky [ ]

###  Thick [ ]  Small [ ]  Slow Growing [ ]  Flat [ ]

###  Spoon shaped [ ]  Curled over end of Toes [ ]  Normal [ ]

### Do you have recurrent nail infections? Yes [ ]  No [ ]

### Are your fingers Missing [ ]  Webbed [ ]  Extra [ ]  Normal [ ]

### Are your toes Missing [ ]  Webbed [ ]  Extra [ ]  Normal [ ]

### Do you have any other finger or toe nail problems? Yes [ ]  No [ ]

### If yes, what are they and have any treatments been successful? Click or tap here to enter text.

## Hair

### Please describe your hair

### Scalp hair? Absent [ ]  Patchy [ ]  Sparse [ ]  Normal [ ]

### Type? Thin [ ]  Brittle [ ]  Fine [ ]  Dry [ ]  Straight [ ]  Curly [ ]

### Colour? Brown [ ]  Black [ ]  Blonde [ ]  Red [ ]

### Is your hair slow growing? Yes [ ]  No [ ]

### Is your beard growth Patchy [ ]  Absent [ ]  Normal [ ]

### Do you wear a wig? Yes [ ]  No [ ]

### Is it natural or synthetic hair? Natural [ ]  Synthetic [ ]

### Did you obtain the wig on the NHS or privately? NHS [ ]  Private [ ]

### Do you have recurrent scalp infections? Yes [ ]  No [ ]

### Do you have any other hair problems? Yes [ ]  No [ ]

### If yes, what are they? Click or tap here to enter text.

### Have any treatments been successful? Yes [ ]  No [ ]

### If yes, what are they? Click or tap here to enter text.

## Joints / Muscles / Skeleton

### Do you have muscle weakness affected by the weather? Hot [ ]  Cold [ ]  Both [ ]  No [ ]

### Do you have regular joint aches affected by the weather? Hot [ ]  Cold [ ]  Both [ ]  No [ ]

### Do you have painful legs? Yes [ ]  No [ ]

### Do you constantly fidget? Yes [ ]  No [ ]

### Have you ever had a broken bone? Yes [ ]  No [ ]

### Do you break bones easily? Yes [ ]  No [ ]

### Do you have difficulty walking? Yes [ ]  No [ ]

### If yes to any of the above, please explain how you are affected Click or tap here to enter text.

### Do you have any skeleton or limb problems including spine issues? Yes [ ]  No [ ]

### If yes, please explain how you are affected Click or tap here to enter text.

## Digestion

### Do you regularly vomit? Yes [ ]  No [ ]

### Do you have regular nausea? Yes [ ]  No [ ]

### Do you suffer with regular constipation? Frequently [ ]  Occasional [ ]  No [ ]

### Do you have bladder problems? Yes [ ]  No [ ]

### Are you tube fed? Yes [ ]  No [ ]

### Have you been tube fed in the past? Yes [ ]  No [ ]

### If yes, please say how long for and what treatments were used? Click or tap here to enter text.

### Do you suffer incontinence? Yes [ ]  No [ ]

### Do you have allergies? Yes [ ]  No [ ]

### If yes, what are they? Click or tap here to enter text.

Do you have any food intolerances? Yes [ ]  No [ ]

If yes, what are they? Click or tap here to enter text.

## Sweat Glands

### Please describe your sweating ability Choose an item

### Do you have lack of temperature control? Yes [ ]  No [ ]

### Are your activities restricted due to the heat or cold? Hot [ ]  Cold [ ]  Both [ ]  Neither [ ]  Do you have frequent high fevers? Yes [ ]  No [ ]

### Do you have behavioural problems when hot/cold? Hot [ ]  Cold [ ]  Both [ ]  No [ ]

### Have you started to sweat? Yes [ ]  No [ ]

### If yes, at what age and how much do you sweat now? Click or tap here to enter text.

### Please describe the cooling aids you use? Air-Conditioning [ ]  Fans [ ]  ChillowPillow [ ]

###  Cooling Jacket [ ]  Cooling Vest [ ]  Wet Hat [ ]

Other please state? Click or tap here to enter text.

### Do you have any other temperature problems? Yes [ ]  No [ ]

### If yes, what are they? Click or tap here to enter text.

### Please describe any other treatments you have found successful Click or tap here to enter text.

## Eyes

### Are your tear ducts Absent [ ]  Blocked [ ]  Normal [ ]

### Are your tears Absent [ ]  Reduced [ ]  Normal [ ]

### Do you have dry eyes? Yes [ ]  No [ ]

### Have you had tear duct replacement? Yes [ ]  No [ ]

### Do you have recurrent conjunctivitis? Yes [ ]  No [ ]

### Do you have blepharitis? Yes [ ]  No [ ]

### Do you have a squint? Yes [ ]  No [ ]

### Do you have retinal detachment? Yes [ ]  No [ ]

### Do you have astigmatism? Yes [ ]  No [ ]

### Do you have in-growing eyelashes? Yes [ ]  No [ ]

Do you have darkly pigmented skin around the eyes? Yes [ ]  No [ ]

Do you have wrinkles around the eyes? Yes [ ]  No [ ]

### Do you wear glasses? Yes [ ]  No [ ]

### Do you have photophobia (light sensitivity)? Yes [ ]  No [ ]

### Are your eyebrows…. Choose an item

### Are your eyelashes…. Choose an item

### Do you have any retinal scarring? Yes [ ]  No [ ]

### Do you have any other eye or vision problems? Yes [ ]  No [ ]

### If yes, what are they? Click or tap here to enter text.

### Please describe any treatments you have found successful Click or tap here to enter text.

## Skin

### What is your body skin condition? Dry [ ]  Splits/Cracks [ ]  Sensitive [ ] Thin [ ]  Normal [ ]

### Do you have eczema? Yes [ ]  Severe [ ]  Mild [ ]  No [ ]

### Do you have body skin infections? Yes [ ]  Severe [ ]  Mild [ ]  No [ ]

### Do you have scalp infections? Yes [ ]  Severe [ ]  Mild [ ]  No [ ]

### Do you have scalp crusting? Yes [ ]  Severe [ ] Mild [ ]  No [ ]

### Do you bruise easily? Yes [ ]  No [ ]

### Do you have thick skin on the soles of your feet? Yes [ ]  Severe [ ] Mild [ ]  No [ ]

### Do you have thick skin on the palms of your hands? Yes [ ]  Severe [ ] Mild [ ]  No [ ]

### Do you have cracks/splits on your fingers? Yes [ ]  Severe [ ] Mild [ ]  No [ ]

### Do you have cracks/splits on your toes? Yes [ ]  Severe [ ]  Mild [ ]  No [ ]

### Is your skin slow to heal? Yes [ ]  No [ ]

### Did you have blisters as a baby? Yes [ ]  No [ ]

### Do you have skin changes when unwell? Yes [ ]  Blotchy [ ]  Pale [ ]  Dark [ ]  No [ ]

### Do you have pigmentation marks? Yes [ ]  No [ ]

### If yes, where are they? Click or tap here to enter text.

### Do you have any other skin problems? Yes [ ]  No [ ]

### If yes, what are they? Click or tap here to enter text.

### Please describe any treatments you have found successful… Click or tap here to enter text.

## Other Problems

### Do you have seizures? Yes [ ]  Frequent [ ]  Occasional [ ]  No [ ]

Are your seizures due to lack of temperature control or epilepsy?

 Temperature hot [ ]  Temperature cold [ ]  Both [ ]  Epilepsy [ ]

### Do you have blackouts (fainting)? Yes [ ]  Frequent [ ]  Occasional [ ]  No [ ]

Are your blackouts due to lack of temperature control?

 Temperature hot [ ]  Temperature cold [ ]  Both [ ]

### Do you have a short stature? Yes [ ]  No [ ]

### Do you take or have you ever taken growth hormones? Yes [ ]  No [ ]

### Are your breasts…. Choose an item

### Are your nipples…. Choose an item

### Do you have delayed sexual development? Yes [ ]  No [ ]

### Do you have delayed mental development? Yes [ ]  No [ ]

### Do you have delayed physical development? Yes [ ]  No [ ]

### Do you have immune problems? Yes [ ]  No [ ]

### If yes, what are they? Click or tap here to enter text.

### Do you suffer anxiety attacks? Yes [ ]  No [ ]

### Do you suffer panic attacks? Yes [ ]  No [ ]

### Do you suffer severe headaches/migraines? Yes [ ]  No [ ]

### Please specify any other problems you suffer with that you feel we should know?

### Click or tap here to enter text.

## Difficulties in School

### Do you have learning difficulties? Yes [ ]  No [ ]

### If so, please explain? Click or tap here to enter text.

### Do you have lack of concentration? Yes [ ]  No [ ]

### Do you have a School Care Plan in place? Yes [ ]  No [ ]

### Do you have a Local Authority Educational Health Care Plan (EHCP)? Yes [ ]  No [ ]

## Infant or early childhood deaths in the family

### Please list any other birth defects or health problems both past and present?

### Click or tap here to enter text.

### Have there been any infant or early childhood deaths in the family? Yes [ ]  No [ ]

### If yes, what age did they die? Choose a number

### Did they have an Ectodermal Dysplasia Syndrome? Yes [ ]  No [ ]  Unknown [ ]

### Are there any other family members who suffer from ED? Click or tap here to enter text.

## Recommendation Medical Professionals

### Can you recommend a Dentist? Click or tap here to enter text.

### Hospital and/or address: Click or tap here to enter text.

### Can you recommend a Geneticist? \_Click or tap here to enter text.

### Hospital and/or address: Click or tap here to enter text.

### Can you recommend a Dermatologist? Click or tap here to enter text.

### Hospital and/or address: Click or tap here to enter text.

### Can you recommend a ENT Specialist? Click or tap here to enter text.

### Hospital and/or address: Click or tap here to enter text.

### Any other specialist? Click or tap here to enter text.

## Disability Living Allowance / Personal Independence Payment / Carers Allowance /Attendance Allowance / Blue Badge - UK Only

If you live in the UK …..

### Do you receive Disability Living Allowance? Yes [ ]  No [ ]

### If yes, which rate do you receive for the care component? Choose an item

### If yes, which rate do you receive for the mobility component? Choose an item

### If no, have you ever applied? Yes [ ]  No [ ]

### Do you receive Personal Independence Payment? Yes [ ]  No [ ]

### If yes, which rate do you receive for the care component? Choose an item

### If yes, which rate do you receive for the mobility component? Choose an item

### If no, have you ever applied? Yes [ ]  No [ ]

### Do you receive Carer’s Allowance? Yes [ ]  No [ ]

### If no, have you ever applied? Yes [ ]  No [ ]

### Do you receive Attendance Allowance? Yes [ ]  No [ ]

### Which rate do you receive for the care component? Choose a item

### Which rate do you receive for the mobility component Choose an item?

### If no, have you ever applied? Yes [ ]  No [ ]

### Did you have to appeal? Yes [ ]  No [ ]

### Did you have to attend a Tribunal? Yes [ ]  No [ ]

### If yes, what was the outcome? Click or tap here to enter text.

### Do you have a Blue Badge? Yes [ ]  No [ ]

### If no, have you ever applied? Yes [ ]  No [ ]

### Did you have to appeal Yes [ ]  No [ ]

### If yes, what was the outcome? Click or tap here to enter text.

## Your Questions

### Are there any specific questions you have? Click or tap here to enter text.

## How would you describe your ethnic group?

**White** [ ]  English / Welsh / Scottish / Northern Irish / British

 [ ]  Irish

 [ ]  Gypsy or Irish Traveler

 [ ]  Any other White background please Click or tap here to enter text.

**Mixed / multiple ethnic groups**

 [ ]  White and Black Caribbean

 [ ]  White and Black African

 [ ]  White and Asian

 [ ]  Any other Mixed / multiple ethnic background please Click or tap here to enter text.

**Asian / Asian British**

 [ ]  Indian

 [ ]  Pakistani

 [ ]  Bangladeshi

 [ ]  Chinese

 [ ]  Any other Asian background please Click or tap here to enter text.

**Black / African / Caribbean / Black British**

 [ ]  African

 [ ]  Caribbean

 [ ]  Any other Black/African/Caribbean background please Click or tap here to enter text.

**Other ethnic group**

 [ ]  Arab

 [ ]  Any other ethnic group please Click or tap here to enter text.

## Website

### If you have visited our website it would be helpful for us to know if you found it easy to use, helpful and if you found the information you were looking for. We would also be grateful for any comments you may have Click or tap here to enter text.

Thank you for completing this questionnaire.

Please return it either by email or post to the address below.

Do please contact us if you are at all worried after answering these questions,

we are here to help.

Please see our website for our Privacy Policy. If you would like to be

removed from our mailing list please contact us on info@edsociety.co.uk

Ectodermal Dysplasia Society

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**Supporting a normal lifestyle**

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