# 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.

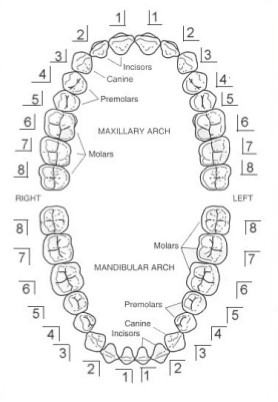
Upper jaw right - Click or tap here to enter text.

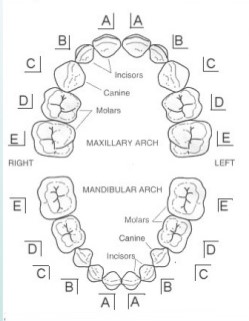
Lower jaw - Click or tap here to enter text.

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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