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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: _____

Address: _____

_____

Male/Female: _____

Date of Birth: _____

Date completed: _____

Telephone Number: _____

Email Address: _____

Your relationship to person with ED: _____

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?

_____

_____

Who made the diagnosis? Geneticist / Dermatologist / Dentist / GP Doctor

If someone else, please state: _____

Teeth

How many teeth do you have? Please circle the number

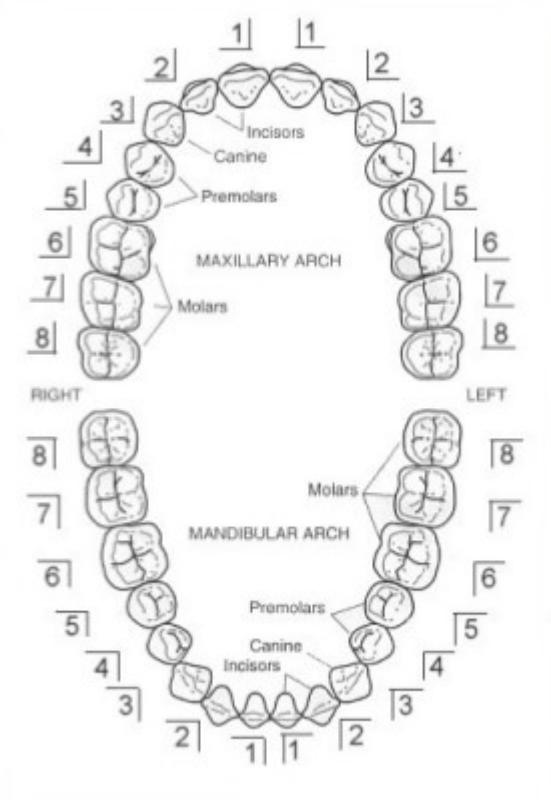
Adult	Upper jaw	- 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
	Lower jaw	- 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Baby	Upper jaw	- 1 2 3 4 5 6 7 8 9 10
	Lower jaw	- 1 2 3 4 5 6 7 8 9 10

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

Adult	Upper jaw left	- 1 2 3 4 5 6 7 8
	Upper jaw right	- 1 2 3 4 5 6 7 8
	Lower jaw left	- 1 2 3 4 5 6 7 8
	Upper jaw right	- 1 2 3 4 5 6 7 8
Baby	Upper jaw left	- A B C D E
	Upper jaw right	- A B C D E
	Lower jaw	- A B C D E
	Upper jaw right	- A B C D E

Adult Teeth

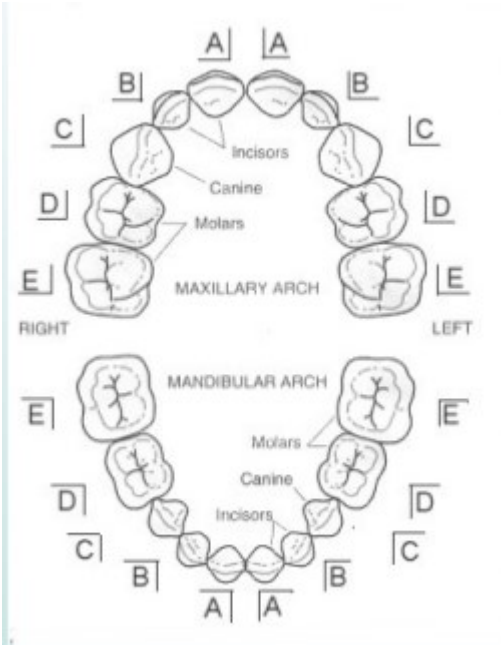
Upper Jaw



Lower Jaw

Baby Teeth

Upper Jaw



Lower Jaw

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

Adult

Upper jaw left - 1 2 3 4 5 6 7 8
Upper jaw right - 1 2 3 4 5 6 7 8

Lower jaw left - 1 2 3 4 5 6 7 8
Upper jaw right- 1 2 3 4 5 6 7 8

Baby

Upper jaw left - A B C D E
Upper jaw right - A B C D E

Lower jaw - A B C D E
Upper jaw right - A B C D E

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 _____

_____

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? _____

_____

Do you have any other teeth/mouth problems? Yes ☐ No ☐

If yes, what are they? _____

_____

Are you currently having any dental work? Yes ☐ No ☐

If yes, please explain? _____

_____

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? _____

_____

Nose

Have you had nasal reconstruction? Yes ☐ No ☐

If yes, when? _____

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 with asthma? Yes ☐ No ☐

Do you have any other nose problems? Yes ☐ No ☐

If yes, what are they? _____

_____

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? _____

_____

Respiratory

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

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? _____

_____

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? _____

_____

Hair

Please describe your hair

Scalp hair? Absent ☐ Patchy ☐ Sparse ☐ Normal ☐

Type? Thin ☐ Brittle ☐ Fine ☐ Dry ☐ Straight ☐ Curly ☐

Colour? Brown ☐ Red ☐ Blonde ☐ Black ☐

Is your hair slow growing? Yes ☐ No ☐

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? _____

_____

Have any treatments been successful? Yes ☐ No ☐

If yes, what are they? _____

_____

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 _____

_____

Do you have any skeleton or limb problems including spine issues? Yes ☐ No ☐

If yes, please explain how you are affected _____

_____

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? _____

_____

_____

Do you suffer incontinence? Yes ☐ No ☐

Do you have any allergies? Yes ☐ No ☐

If yes, what are they? _____

_____

Do you have any intolerances? Yes ☐ No ☐

If yes, what are they? _____

_____

Sweat Glands

Please describe your sweating ability Absent ☐ Decreased ☐ Excessive ☐

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? _____

_____

Please describe the cooling aids you use? Air-Conditioning ☐ Fans ☐ ChillowPillow ☐

Cooling Jacket ☐ Cooling Vest ☐ Wet Hat ☐

Other please state? _____

Do you have any other temperature problems? Yes ☐ No ☐

If yes, what are they? _____

_____

Please describe any other treatments you have found successful _____

_____

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…. Absent ☐ Sparse ☐ Normal ☐

Are your eyelashes…. Absent ☐ Sparse ☐ Normal ☐

Do you have any retinal scarring? Yes ☐ No ☐

Do you have any other eye or vision problems? Yes ☐ No ☐

If yes, what are they? _____

_____

Please describe any treatments you have found successful _____

_____

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 sole of feet? Yes ☐ Severe ☐ Mild ☐ No ☐

Do you have thick skin on palms of 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? _____

_____

Do you have any other skin problems? Yes ☐ No ☐

If yes, what are they? _____

_____

Please describe any treatments you have found successful… _____

_____

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…. Left absent ☐ Right absent ☐ Left underdeveloped ☐

Right underdeveloped ☐ Both underdeveloped ☐ Normal ☐

Are your nipples…. Left absent ☐ Right absent ☐ Left underdeveloped ☐

Right underdeveloped ☐ Both underdeveloped ☐ Normal ☐

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? _____

_____

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?

_____

_____

Difficulties in School

Do you have learning difficulties? Yes ☐ No ☐

If so, please explain? _____

_____

Do you have lack of concentration? Yes ☐ No ☐

Do you have a School Care Plan? 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?

_____

_____

Have there been any infant or early childhood deaths in the family? Yes ☐ No ☐

If yes, what age did they die? 1 2 3 4 5 6 7 years old

Did they have an Ectodermal Dysplasia Syndrome? Yes ☐ No ☐ Unknown ☐

Any other family members suffer from ED? _____

_____

Recommendation Medical Professionals

Can you recommend a Dentist? _____

Hospital and/or address: _____

_____

Can you recommend a Geneticist? _____

Hospital and/or address: _____

_____

Can you recommend a Dermatologist? _____

Hospital and/or address: _____

_____

Can you recommend a ENT Specialist? _____

Hospital and/or address: _____

_____

Any other specialist? _____

_____

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?

High Rate ☐ Middle Rate ☐ Low Rate ☐

If yes, which rate do you receive for the mobility component?

High Rate ☐ Low Rate ☐

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?

Standard Rate ☐ Middle Rate ☐ Low Rate ☐

If yes, which rate do you receive for the mobility component?

Standard Rate ☐ Enhanced Rate ☐

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? High Rate ☐ Low Rate ☐

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? _____

_____

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? _____

_____

Your Questions

Are there any specific questions you have? _____

_____

_____

_____

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 _____

_____

_____

_____

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.

Ectodermal Dysplasia Society
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