

Symptoms Questionnaire

This questionnaire has been designed to enable the Ectodermal Dysplasia Society to obtain as much information as possible regarding the symptoms you or your child experience so we can help you. We will use this information to answer your questions, worries and concerns.

We can

- help you find specialist help regarding your health issues, teeth, skin, eyes, ears, etc.
- support families when they approach organisations such as Local Authorities, Social Services, medical professionals, etc., by putting together a personal report explaining very simply the affects of Ectodermal Dysplasia and how to manage them
- help families get the right care for their child in school, such as fans, air-conditioning, school health care plan, etc., by liaising with Head Teachers, Health Authorities and medical professionals
- liaise with individuals, families, professionals and members of the Medical Advisory Board with the aim of providing personal support and advice to those affected by Ectodermal Dysplasia
- help more families obtain Disability Living Allowance, Personal Independent Payment, Disability Carers Allowance, etc.

Please complete the following questions as fully as possible. If there is not 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 by you will be completely confidential and will not be shared with any third party without your express permission.

Incontinentia Pigmenti is an Ectodermal Dysplasia syndrome and has many of the symptoms associated with Ectodermal Dysplasia.

Personal Details

Name of person with ED:

Address:

Male/Female:

Date of Birth:

Date completed:

Telephone Number:

Email Address:

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

General Patient Information

Has a specific diagnosis for an Ectodermal Dysplasia syndrome been made? Yes No

If so, what type of Ectodermal Dysplasia has been diagnosed? Click or tap here to enter text.

When was the diagnosis made? 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.

Bladder and Intestines

Do you suffer incontinence? Yes No

Do you have renal agenesis (absence of kidney)? Yes No

Do you have narrowing tubes (ureters) that carry urine? Yes No

Do you suffer obstruction of the tubes? Yes No

Do you suffer atrophic (small) bladder? Yes No

Do you suffer thinning of the bladder lining? Yes No

Do you suffer with regular constipation? Frequently Occasional No

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

Digestion

Do you regularly vomit? Yes No

Do you have regular nausea? 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 have food 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.](#)

Ears

Do you have nerve or other deafness? Yes No

Do you wear hearing aids? Yes No

Do you have cochlear implants? 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.](#)

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 <input type="checkbox"/>	No <input type="checkbox"/>
Do you have recurrent conjunctivitis?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Do you have blepharitis?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Do you have a squint?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Do you have astigmatism?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Do you have in-growing eyelashes?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Do you have darkly pigmented skin around the eyes?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Do you have wrinkles around the eyes?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Do you wear glasses?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Do you have photophobia (light sensitivity)?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Are your eyebrows....	Choose an item	
Are your eyelashes....	Choose an item	
Do you have any other eye or vision problems?	Yes <input type="checkbox"/>	No <input type="checkbox"/>

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.](#)

Eyes - Incontinentia Pigmenti

Have you had your eyes screened?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
If yes, were you offered eye screening from birth?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
If no, how soon after birth were your eyes screened?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Do you have retinal detachment?	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Do you have any retinal scarring? Yes No

Fingers and Toes

Please describe your fingernails

Weak Ridged Brittle Flaky
Thick Small Slow Growing Flat
Spoon shaped Normal N/A

Please describe your toenails

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 toenail 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 N/A

Do you wear a wig? Yes No

Is your wig 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 / Skeletal

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 skeletal or limb problems including spine issues? Yes No

If yes, please explain how you are affected [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

When do you have nosebleeds

during the night

during the day

both

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 have any other nose 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 suffer recurrent chest infections?

Yes

No

Do you suffer with asthma?

Yes

No

Do you use a humidifier?

Yes

No

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.](#)

Sleep

- Do you bed wet? 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.](#)

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.](#)

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 teeth are missing altogether and which of the top and bottom four front teeth are pointed or misshapen? Please enter the numbers or letters

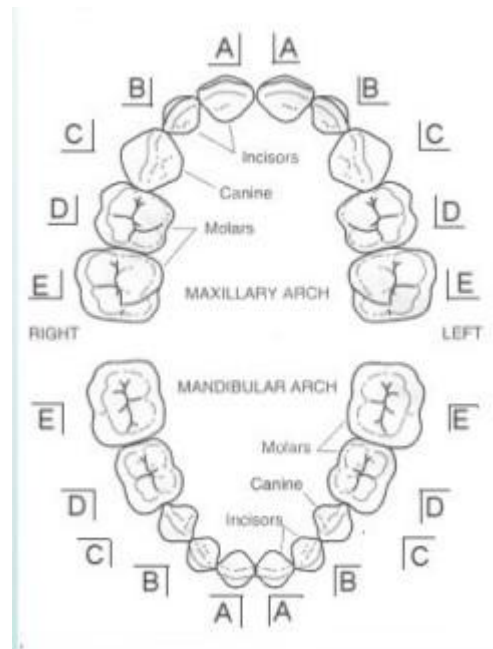
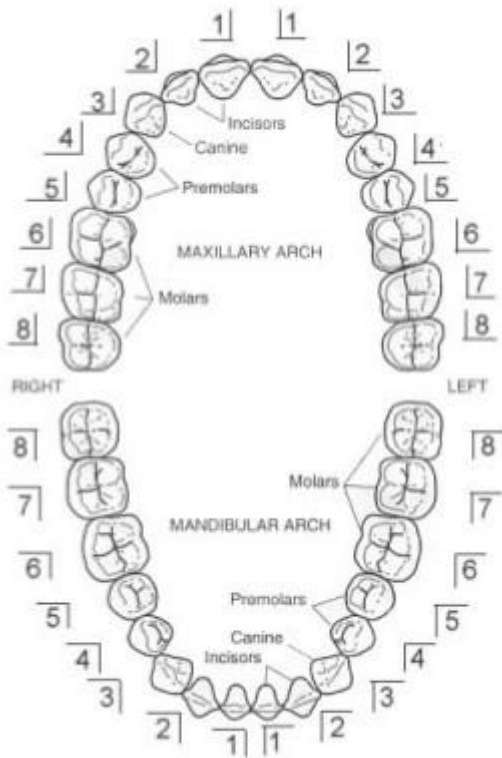
- Adult
 - Upper jaw left - Click or tap here to enter text.
 - Upper jaw right - Click or tap here to enter text.
 - Lower jaw left - Click or tap here to enter text.
 - Upper jaw right - Click or tap here to enter text.
- Baby
 - Upper jaw left - Click or tap here to enter text.
 - Upper jaw right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

Upper Jaw

Baby Teeth

Upper Jaw



Lower Jaw

Lower

Jaw

Do you have dental implants?

Yes

No

Did your Dentist have difficulty putting the implants in?

Yes

No

Did you have bone grafting?

Yes

No

Is your jawbone density very hard?

Yes

No

Were your implants successful?

Yes

No

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

Do you wear dentures?

Yes

No

Did or do you have a cleft palate?

Yes

No

Did or do 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.](#)

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 recurrent choking? Yes No

Do you have swallowing difficulty? Yes No

Do you have gastroesophageal reflux? Yes No

Do you have a hoarse voice? Yes No

Do you suffer with recurrent tonsilitis? Yes No

Have you had your tonsils removed? Yes No

Have you had your adenoids removed? Yes No

Do you have any other throat problems? Yes No

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

Other Problems

Do you have bladder problems? Yes No

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 high Temperature low 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

If yes, please try to say what causes them? Click or tap here to enter text.

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 yes, 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

Does the School understand your needs? Yes No

Do you have air-conditioning or a fan in your classroom? Yes No

Birth Defects and Family History

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 were they when this happened? 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 (DLA) / Personal Independence Payment (PIP) / 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

Have you had to appeal for any allowance? Yes No

Did you have to attend a Tribunal for any allowance? Yes No

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

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

Have you had to appeal for any allowance? Yes No

Did you have to attend a Tribunal for any allowance? Yes No

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

Do you receive Carers' 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

If no, have you ever applied? Yes No

Have you had to appeal for any allowance? Yes No

Did you have to attend a Tribunal for any allowance? 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.](#)

Rather Not Say

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.

Please return this Questionnaire by either 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

Patron: Francesca Jones

Ectodermal Dysplasia Society
Unit 1 Maida Vale Business Centre, Cheltenham, Glos. GL53 7ER England
Tel: +44 (0) 1242 261332 Mobile +44 (0) 7774 465712
Email: diana@edsociety.co.uk
Website: www.edsociety.co.uk

Supporting a normal lifestyle

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