

Support for Families and Carers (How To Guides - UK)

Below are step-by-step instructions and additional guidance for key practical support you can apply for when living with Xeroderma Pigmentosum (XP).

Blue Badge (Disabled Parking)

A **Blue Badge** allows you to park closer to shops, schools, hospitals and services. For families affected by XP, this can significantly reduce daylight exposure and walking distance.

Who Can Apply

You may qualify automatically if you:

- Receive the **higher rate mobility component of DLA**
- Receive **PIP mobility component (8+ points under “moving around”)**
- Are registered blind (severely sight impaired)

You may also qualify if:

- You cannot walk far without severe difficulty
- Walking outdoors causes serious risk to your health (this can apply in XP due to UV exposure risk)
- You regularly need supervision outdoors for safety

Each application is assessed by your **local council**.

Steps to Apply

1. Visit the official Government portal:
<https://www.gov.uk/apply-blue-badge>
2. Apply through your local council (search your postcode on the page).
3. Prepare documents:
 - Photo ID (passport or driving licence)
 - Proof of address (utility bill, council tax letter)

- Recent passport-style photo
 - Benefit award letter (DLA, PIP)
 - Medical evidence (clinic letters confirming XP diagnosis and UV risk)
4. Complete the form online (or request a paper copy).
 5. Some councils may request:
 - A mobility assessment
 - Further medical clarification
 6. Wait for a decision (usually 6-12 weeks).

Helpful Tips for XP Applications

- Clearly explain that UV exposure presents a **serious health risk**, not just discomfort.
 - Describe how proximity parking reduces cancer risk and neurological risk.
 - Include clinic letters where possible.
 - If refused, you can request a review or appeal.
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Disability Living Allowance (DLA) / Personal Independence Payment (PIP)

DLA (for children under 16) and PIP (for adults 16+) provide financial support for extra care and mobility needs.

XP often qualifies due to:

- Continuous supervision needs
 - Protective routines
 - Environmental adaptations
 - Restricted outdoor mobility
 - Neurological or developmental impact (in some individuals)
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Applying for DLA (Child under 16)

Official page: <https://www.gov.uk/disability-living-allowance-children>

Steps

1. Call the Disability Living Allowance helpline to request a form:
0800 121 4600
 2. Complete the detailed form explaining:
 - Care needs day and night
 - Supervision required outdoors
 - Dressing/undressing for UV protection
 - Monitoring and protection routines
 3. Include evidence:
 - Dermatology letters
 - Genetic diagnosis confirmation
 - Photos of adaptations (window film, visors)
 - Education plans (if relevant)
 4. Return by post (keep a copy or scan).
 5. Decision usually within 8-12 weeks.
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Applying for PIP (Age 16+)

Official page: <https://www.gov.uk/PIP>

Steps

1. Start claim by phone: 0800 917 2222
2. Complete “How your disability affects you” form.
3. Provide detailed examples:
 - Why independent outdoor mobility is unsafe
 - How UV exposure risk limits normal life
 - Psychological impact
4. Attend assessment (if required).
5. Receive decision letter.

Important Tip

Always describe:

- Your **worst days**
- The **safest possible scenario**
- What happens without protection
- Risks of skin cancers and neurological complications

You may want support from:

- Citizens Advice - <https://www.citizensadvice.org.uk>
 - Scope - <https://www.scope.org.uk>
 - Contact (for families) - <https://contact.org.uk>
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NHS Travel Reimbursements & Travel Grants

Frequent hospital visits are common for XP monitoring.

NHS Healthcare Travel Costs Scheme (HTCS)

You may claim travel costs if:

- You receive certain benefits (e.g. Universal Credit, Income Support)
- You are referred by a GP or consultant

Official page:

<https://www.nhs.uk/nhs-services/help-with-health-costs/healthcare-travel-costs-scheme-htcs/>

Steps

1. Keep all receipts (petrol, train tickets, parking).
2. Claim at hospital cashier's office same day OR
3. Complete HC5(T) form if claiming later.
4. Payment processed after assessment.

Claim NHS support first before approaching charities.

Charity Travel Grants

Some charities may help with:

- Long-distance specialist appointments



- Overnight accommodation
- Fuel costs not covered by NHS

Examples:

- Family Fund - <https://www.familyfund.org.uk>
- Ronald McDonald House (hospital stays) - <https://rmhc.org.uk>

Check eligibility carefully.

Grants for UV Protective Film (Home & Vehicle)

UV-blocking film is essential for safe indoor living.

XP patients require film that:

- Blocks 99-100% of UV radiation
 - Allows visible light where possible
 - Is professionally installed
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Step 1: Disabled Facilities Grant (DFG)

Official page: <https://www.gov.uk/disabled-facilities-grants>

DFGs can cover:

- Window adaptations
- Structural safety adjustments
- Environmental health adaptations

Steps

1. Contact your local council housing department.
2. Request assessment for Disabled Facilities Grant.
3. Provide:



- Medical evidence
- Occupational therapy report (if available)
- Quotes from installers

Means-tested for adults (not means-tested for children).

Step 2: Speak to Your Specialist Clinic

Ask:

- If they can provide a supporting medical letter.
- Whether they recommend specific UV film suppliers.

Step 3: Charitable Support

If DFG is unavailable:

- Speak to your support charity.
- Apply for hardship or equipment grants.

Also explore:

- Turn2Us grant search - <https://www.turn2us.org.uk>
- Family Fund (for children under 18)

Additional Support Families Should Explore

Education, Health and Care Plans (EHCP)

If XP affects schooling, apply via your local authority:

<https://www.gov.uk/children-with-special-educational-needs>

Energy Support



XP households may use higher electricity (cooling systems, safe lighting).
Check:

- Priority Services Register (energy suppliers)
- Warm Home Discount

Carer's Allowance

If you provide 35+ hours care weekly: <https://www.gov.uk/carers-allowance>

Final Advice for Families

- Keep copies of everything.
- Use medical letters wherever possible.
- Clearly explain UV exposure risk.
- Don't minimise impact, describe real daily effort.
- Seek advice early if unsure.