



# A Parent's Guide to Completing the DLA Form for a Child with XP

XP is rare, complex and life-limiting. Standard DLA tick boxes often do not fully reflect the reality of raising a child who must live a 100% UV-avoidance lifestyle.

This guide will help you:

- Explain XP clearly
  - Evidence the extra care and supervision required
  - Avoid under-reporting your child's needs
  - Use the form to its full potential
- 

## 1. Before You Start

### Understand What DLA Is Assessing

DLA for children looks at:

- Care needs (day and night)
- Mobility needs
- Needs that are substantially more than a child of the same age without a disability

It is not about diagnosis alone, it is about:

The extra help, supervision, protection, and care your child needs because of XP.

---

## 2. Explaining XP (Medical Conditions Section)

In the section asking about illnesses or disabilities:

Always include:

- Full diagnosis: Xeroderma Pigmentosum
- That it is genetic
- That it is incurable
- That there is no treatment to reduce UV damage
- That UV exposure causes permanent cumulative DNA damage
- That risk of skin cancer is dramatically increased
- That complete UV avoidance is the only life-preserving management

Be clear:

- XP is present from birth
- Risk exists in:
  - All daylight (even cloudy days)
  - Through glass
  - From many artificial light sources

When listing treatment include:

- SPF 50+ broad spectrum sunscreen (frequency, e.g. every 2–3 hours)
- Vitamin D supplementation (daily)
- UV protective clothing
- Face visor/shield
- Gloves
- UV window film (home and car)
- Use of UV light meter
- Specialist hospital monitoring

Explain frequency precisely.

Instead of:

“Sun cream applied regularly”

Write:

“Full body SPF 50+ sunscreen applied every 2–3 hours daily. Each application takes approximately 20 minutes and requires full adult supervision.”

---

### 3. Aids and Adaptations

List everything, even if it feels “normal” to you.

Examples:

- Specialist UV protective clothing
- Full face visor
- UV protective gloves
- UV window film (house and car)
- UV light meter
- Blackout blinds
- Adapted vehicle

Explain:

- Who checks them
- Who maintains them
- What happens if they fail
- That your child cannot assess UV risk themselves



Be explicit:

“My child is fully reliant on adults to test environments with a UV meter before entering.”

---

## 4. Mobility Section - How XP Affects Mobility

Important: XP often does not affect the ability to physically walk, but it dramatically affects safe mobility outdoors.

Explain clearly:

- Child cannot safely go outside during daylight without full protection.
- Public transport is unsafe.
- Only adapted vehicles can be used.
- Protective equipment:
  - Distorts vision
  - Affects hearing
  - Causes overheating
  - Causes dehydration risk
- Child cannot independently manage protective equipment.
- Child may remove gloves/visor (constant supervision required).
- Environment must be tested for UV before entering.

If your child is physically able to walk but functionally unable to access the outside world safely, explain that in detail.

DLA decision makers must understand:

The restriction is environmental and life-threatening, not muscular.

---

## 5. Supervision Outdoors

Most children with XP require:

- Constant 1-to-1 supervision
- Monitoring of:
  - Clothing integrity (no rolled sleeves, removed gloves)
  - Hat/visor position
  - UV levels
- Prevention of accidental exposure by others (e.g. curious children lifting visor)
- Monitoring for overheating
- Monitoring for dehydration

Explain why this is significantly more than a typical child of the same age.

## 6. Care Needs - Daytime

This is where many XP claims are under-reported.

Break everything down into:

- How often?
- How long?
- What happens if not done?

### Toileting

Explain:

- Toileting must occur in UV safe environments.
- Clothing removal increases risk.
- Sunscreen may need reapplying after washing.
- Public toilets may be unsafe due to lighting/windows.

### Washing & Bathing

- Requires UV safe environment.
- Sunscreen reapplication afterwards.
- Skin checks for lesions or changes.

### Dressing

- Time required to layer protective clothing.
- Checking for gaps.
- Repairing or replacing damaged items.
- Testing clothing integrity.

### Eating & Drinking

- Cannot remove visor/gloves in unsafe environments.
- Requires adult to assist with drinking/eating.
- Needs encouragement to drink to avoid dehydration.

### Medication & Monitoring

- Vitamin D daily.
- Repeated sunscreen application.
- Monitoring for:
  - Skin changes

- Neurological deterioration
- Vision/hearing changes

Explain emotional impact:

- Distress during repeated sunscreen applications.
  - Frustration with restrictive clothing.
- 

## 7. Supervision for Safety

XP requires supervision not just for behaviour but for survival.

Explain:

Your child:

- Cannot recognise UV danger.
- Cannot assess safe environments.
- Cannot test lighting.
- Cannot manage exposure risk.
- May remove protective equipment impulsively.
- Is at constant risk of irreversible harm if supervision lapses.

State clearly:

“Failure to comply with protective measures at any time results in permanent DNA damage.”

---

## 8. Development & Play

XP affects normal childhood development because:

- Outdoor play is severely restricted.
- Gloves reduce dexterity.
- Visor affects vision and hearing.
- Limited access to spontaneous play.
- Social isolation risks.

Explain:

- Extra planning required for any activity.
  - Adult supervision required for all play outside protected home.
  - Need for EHCP or 1-to-1 support at school.
- 

## 9. Night-Time Needs

Often children with XP:

- Are safe at night in adapted home
- But still require monitoring of artificial lighting when outside home

- May have disrupted sleep due to routine restrictions
- Only include what genuinely applies.
- 

## 10. Extra Information Section (Use It!)

This section is critical for rare conditions like XP.

Use it to clearly state:

- XP is extremely rare.
- It is life-threatening.
- Protection levels in childhood determine life expectancy.
- A “one size fits all” assessment does not reflect this condition.
- Your child requires complete UV avoidance for life.

Summarise impact in bullet form if helpful.

---

## 11. Language That Helps

Use:

- “Constant supervision”
- “Life-preserving measures”
- “Permanent cumulative DNA damage”
- “Cannot safely access community independently”
- “Significantly more care than a child of the same age”

Avoid:

- Minimising language
  - “We manage”
  - “It’s fine”
  - “He’s coping”
- 

## 12. Final Checklist Before Sending

- Have you described:
  - Sunscreen frequency?
  - Clothing checks?
  - Environmental testing?
  - Emotional distress?
  - Social restriction?
  - Dehydration risk?
  - Overheating risk?



- Have you compared to a child of the same age?
  - Have you explained risk of permanent damage?
  - Have you used the Extra Information page fully?
  - Have you included supporting medical evidence?
- 

## Final Thoughts

Raising a child with Xeroderma Pigmentosum means living a life of constant vigilance. DLA decision makers may never have encountered XP before.

Your job in this form is to make them understand:

- The risk is invisible.
- The protection is relentless.
- The supervision is constant.
- The consequences of failure are life-threatening.

Do not understate the reality.