

A Practical Guide to Completing a PIP Application for Adults with XP

Personal Independence Payment (PIP) is not awarded based on diagnosis alone.

It is awarded based on:

- How your condition affects your daily living
- How it affects your mobility
- Whether you can carry out activities:
 - Safely
 - To an acceptable standard
 - Repeatedly
 - Within a reasonable time

XP is rare. Many assessors will have never encountered it before.

Your form must clearly explain the functional consequences of lifelong UV avoidance.

1. Before You Start

Understand what PIP assesses:

Daily Living (10 activities)

Including:

- Preparing food
- Eating and drinking
- Washing and bathing
- Managing toilet needs
- Dressing
- Communicating
- Engaging with others
- Managing treatments

Mobility (2 activities)

- Planning and following journeys
- Moving around

XP affects both areas but often in ways that are not immediately obvious.

2. Explaining XP (Health Conditions Section)

In the health conditions section, clearly state:

- Xeroderma Pigmentosum (XP)
- Genetic DNA repair disorder
- Incurable
- No treatment to reduce UV damage
- 10,000x increased risk of skin cancer (if relevant to your subtype)
- UV exposure causes permanent cumulative DNA damage
- Complete photoprotection is required for life preservation

Explain clearly that UV exposure occurs from:

- Daylight (even cloudy days)
- Through untreated glass
- Many artificial light sources

Use direct language such as:

“Failure to maintain strict photoprotection results in irreversible DNA damage and significantly increased risk of aggressive skin cancers.”

3. Managing Treatments (Daily Living Activity)

PIP looks at whether you can manage therapy safely and independently.

Adults with XP may need to explain:

- Full-body SPF 50+ sunscreen every 2–3 hours during daylight
- Time required (often 15-30 minutes per application)
- Need for private UV-safe space to reapply
- Vitamin D supplementation
- Skin inspections for suspicious lesions
- Specialist dermatology follow-up
- Use of UV light meter to assess environments

Explain if:

- You rely on someone to help apply sunscreen to hard-to-see areas
- Someone checks your skin
- You need prompting to reapply
- You cannot safely apply it while out due to lack of safe spaces

Describe the time burden, PIP considers therapy lasting over 3.5 hours per week significant.

4. Preparing & Eating Food

When outside a safe space:

- You may need to wear a full visor and gloves.
- Eating can be physically difficult.
- Drinking from bottles may expose your face.
- Food must be carefully selected (e.g., dry finger food).
- Gloves reduce dexterity.
- Wet gloves reduce UV protection.
- You may need specialist cups or straws.

Explain clearly:

- If someone needs to assist you
 - If you avoid eating outside home due to risk
 - If it causes distress or fatigue
 - If overheating limits time out
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5. Washing and Bathing

Explain:

- You can only undress in a UV-safe environment.
- Bathrooms must have UV-filtered windows and safe lighting.
- You cannot safely wash in most hotels or unfamiliar homes.
- Windows cannot be opened due to UV risk.
- Ventilation must be adapted.

If you need:

- Assistance checking lighting
- Help adapting environments
- Support when travelling

State this clearly.

6. Managing Toilet Needs

Explain:

- Toilets must be UV-safe.
- Public toilets may be unsafe due to lighting or windows.
- You may need to:
 - Use adapted vehicle as safe space

- Use UV shield/cover
- Carry a urine bottle
- You cannot use open urinals.
- Clothing removal increases exposure risk.

If incontinence is present, describe:

- Frequency
- Night-time issues
- Hygiene challenges
- Need for assistance

Be specific and factual.

7. Dressing and Undressing

Describe:

- Full UV protective layering
- Gloves, base layers, visor, hat
- Checking for gaps
- Clothing integrity checks
- Testing with UV meter
- Time burden

If you need prompting or help to:

- Maintain compliance
- Replace damaged items
- Repair protective gear

Explain this.

8. Communication

The visor can cause:

- Sound distortion
- Reduced hearing clarity
- Difficulty projecting voice
- Echo effect
- Difficulty in background noise
- Increased anxiety in public

Explain:

- Others sometimes speak for you

- You struggle at service counters
 - You cannot remove visor when asked
 - You experience social anxiety due to appearance
 - Wind, rain and fogging impair vision and hearing
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9. Engaging with Other People

XP often leads to:

- Social isolation
- Anxiety about public reactions
- Fear of confrontation
- Reluctance to attend unfamiliar places
- Need for emotional support

If you are under psychological care, mention this.

Explain:

- You require reassurance before going out
 - You avoid social events due to risk
 - You feel self-conscious wearing protection
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10. Planning and Following Journeys (Mobility Activity 1)

This is one of the most relevant sections for XP.

Explain:

- All journeys must be planned in advance.
- You must assess UV risk.
- You rely on a UV meter.
- You may need to:
 - Black out windows
 - Change light bulbs
 - Confirm lighting safety
- You experience anxiety about unknown environments.
- Overheating risk limits duration outdoors.
- Weather significantly affects safety.
- You may be unable to travel alone safely.

If you cannot visit unfamiliar places without assistance, state this clearly.

11. Moving Around (Mobility Activity 2)

Physically you may walk normally.

However explain:

- You can only be outside during certain times.
- Protective clothing causes overheating.
- Visor distorts vision.
- Rain, snow and glare increase risk.
- Gloves reduce grip.
- Hearing is distorted (traffic risk).
- You may need to limit distance due to temperature.

Make clear:

Physical walking ability is not the only issue, environmental risk makes walking unsafe without strict conditions.

12. Safety & Supervision

PIP considers whether you can carry out activities:

- Safely
- Repeatedly
- To acceptable standard

State clearly:

- Even brief UV exposure causes irreversible harm.
 - You cannot “risk manage” casually.
 - You require constant vigilance.
 - If equipment fails, you are at immediate risk.
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13. Face-to-Face Assessment Adjustments

If an assessment is required, request:

- UV-safe room
- No windows or fully blacked out
- LED lighting confirmed safe
- Opportunity to test environment with UV meter
- Option for home assessment

Explain clearly that you cannot remove protective equipment in unsafe conditions.

14. Language That Strengthens Your Application

Use phrases like:

- “Permanent cumulative DNA damage”
- “Life-preserving measures”
- “Cannot safely access community independently”
- “Strict photoprotection required”
- “High risk of aggressive skin cancers”
- “Activity cannot be performed safely without adaptations”

Avoid minimising language such as:

- “I manage”
 - “I cope”
 - “It’s fine”
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15. Final Checklist Before Sending

Have you explained:

- Sunscreen frequency and time burden?
- Clothing checks and maintenance?
- Environmental testing?
- Emotional impact?
- Overheating and dehydration?
- Communication barriers?
- Journey planning anxiety?
- That assessors may not understand XP?

Have you clearly linked:

Each difficulty → To a PIP activity descriptor?

Final Thoughts

Living with Xeroderma Pigmentosum means living a life of:

- Constant vigilance
- Environmental risk assessment
- Protective layering
- Social and emotional burden
- Physical discomfort
- Long-term cancer risk



PIP assessors may never have assessed someone with XP before.

Your role in the form is to ensure they understand:

- The risk is invisible.
- The protection is relentless.
- The consequences of error are permanent.