

Skin Picking in People with Prader-Willi syndrome

Skin picking or scratching is a common behaviour seen in people with Prader-Willi Syndrome (PWS). The intensity and duration of this behaviour varies from person to person and episode to episode. It may occur in the form of scratching an insect bite until it bleeds and becomes an infected sore or it may manifest in the form of nose picking or anal picking. When this behaviour continues for a prolonged period it can cause unsightly and distressing open wounds. 75% of the people surveyed by FamCare reported skin picking in their relative with PWS. A USA study reported anal picking in 9.5 % of people who skin picked.

Why do people with PWS skin pick?

The behaviour is thought to start in response to boredom, stress and anxiety or as a form of self-stimulation. It is also known that people with PWS have a high pain threshold and do not feel pain so intensely. Once commenced it is difficult for the person with PWS to cease the behaviour without some form of external intervention, as they become “stuck” in the behaviour.

If the underlying cause of the skin picking can be identified, especially where stress or anxiety is thought to be a contributing factor, the ideal would be to investigate and discuss what is causing the stress for the person with PWS. If the stress can be removed or decreased, the skin picking should also reduce. Remember, however, that the picking may continue as it may have built up to a repetitive behaviour which will take longer to stop.

What works to avoid skin picking

There are simple and practical strategies that help to minimise the severity and frequency of skin picking, despite the fact that it may still occur spasmodically.

These include:

- routine cutting of finger nails eg weekly
- daily use of moisturiser for fingers, hands and arms
 - ❖ it is best if the moisturiser is applied by the person with PWS
- positive reinforcement for “healthy, good-looking skin”
- keeping hands occupied – using a “word-find” or puzzle book, computerised game use, object kneading – eg soft ball, worry beads, hand craft – such as knitting, crocheting, beading, unravelling woven blankets
- daily sensory stimulation of the hands and arms – eg massage
- maintaining a PWS appropriate and calm environment
- brushing hair daily for a number of strokes, counted – eg 50, encourages the growth of “beautiful, shiny hair” when the habit of pulling hair out, is a problem.

What works to limit skin picking while it is occurring?

Skin picking often occurs in waves. These can be hard to work through but it is possible to lengthen the time between episodes and shorten the actual periods of skin picking.

Below is a list of strategies that parents and carers have found successful to reduce this behaviour

- tell the person how wonderful their “unpicked” skin is
- tell the person you want to help their *sore* to heal
- give verbal praise for periods of time spent not picking
- offer the person a reward(not food) for time spent not picking – this can be for a few hours or lengthened to days or at the end of a week for 7 days of no picking. Drawing up a *contract* involving “periods of non picking” often works well.
- keep hands occupied at vulnerable times (see above)

If anal picking is a problem rolling balls of toilet paper while sitting on the toilet may keep hands occupied

- try *not* to focus on or talk about the skin picking
- using distracting calming strategies and verbal re-directive strategies eg, asking the person to tell you about something that interests them
- dress any picked sores with antiseptic cream if necessary
- cover the picked area with a gauze dressing and bandage to prevent access to the area
- maintain supervision of the person if they are only picking in secret – but nighttimes are difficult
- try using a strong solution of salt and warm water to bathe picked areas
- an Aloe Vera based cream works very well on the sores
- using Calamine lotion to cover the area and make less attention attracting
- in severe cases medication (*only* prescribed by a doctor) may be beneficial –
eg Topiramate, topical Bactroban, ReVia (naltrexone hydrochloride)

All medications must be monitored by a doctor to prevent any reactions within the person with PWS

Skin picking does not occur all the time. Prevention is always the better option, however, techniques used to avoid skin picking need to be practised regularly – as with all PWS management.