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.

**Why do people with PWS skin pick?**

The behaviour is thought to be initiated in response to boredom, stress or as a form of self-stimulation. 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.

**What works to avoid the behaviour**

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
  - an Aloe Vera based cream works very well
  - it is best if the moisturiser is applied by the person with PWS, themselves
- positive reinforcement for “healthy, good-looking skin”
- keeping hands occupied – using a “word-find” or puzzle book, computerised game use, object kneading – soft ball, worry beads, hand craft –eg knitting, crocheting, beading
- maintaining a PWS appropriate and calm environment

Brushing hair daily for a count of strokes – eg 50, encourages the growth “beautiful, shiny hair” when the habit of pulling hair out, is a problem.
What works to arrest the behaviour?
If the underlying causes of the skin picking can be identified, especially where stress is thought to be a contributing factor, the ideal would be to discuss what is causing the stress with the person with PWS. If the stress can removed altogether, then the skin picking should also reduce. Remember, however, that the picking will have been repeated and may have built up to repetitive behaviour that may take time to cease altogether.

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
- offer much 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 to days and/or an accumulative one – at the end of week for 7 days of no picking
- keep hands occupied at vulnerable times eg, rolling balls of toilet paper while sitting on the toilet
- do not focus on the actual skin picking
- implementing distracting calming strategies, verbal re-directive strategies
- dress the open area 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
- using a strong solution of salt and warm water to bathe picked areas
- using Calamine lotion to cover the area and make less attention attracting
- in severe cases medication (prescribed by a doctor) may be beneficial – eg Topiramate, topical Bactroban

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