



“Personal Care” For People with Prader-Willi syndrome

Personal care is an important part of everybody's daily routine. However some people with Prader-Willi Syndrome (PWS) have a reluctance, or a reduced ability to complete personal care routines properly. For example, factors such as obesity or lack of coordination can make it difficult for a person with PWS to reach all areas of their own body, and a lack of motivation or time can impact the care and thoroughness of cleaning routines. Poor sequential processing or difficulty in completing multi-stepped tasks, often inhibits the thoroughness of washing, for example: the person with PWS may just stand under a shower rather than wash themselves. While some people with PWS take a lot of pride in their appearance others are not concerned about their appearance and are insensitive to social hygiene expectations. Lack of routine personal care can lead to health issues such as tooth decay and skin infections. Poor hygiene can also impact negatively on socialisation and create a barrier to forming friendships. It can also trigger conflict with parents, siblings, fellow house residents and co-workers. Some people with PWS are not aware of this issue and may need you to explain it to them and remind them of the importance of routine personal care.

People with PWS are often prone to infections due to skin picking, poor blood circulation, poor hygiene, dry skin and diabetes. Their feet can need extra care such as orthotics and regular moisturising, and even the correct positioning of socks and shoes to prevent blisters.

People with PWS often have dental problems, exacerbated by teeth grinding and heavy consumption of acidic or sugary food and drinks. A strict routine for effective cleaning teeth is vital to help prevent tooth and gum deterioration. Good personal care usually require the help of family or carers.

Managing the Needed Routine of Personal Care

The person with PWS needs to routinely wash hands with soap and dry them well, after each visit to the bathroom. Handwashing should also be encouraged before meals and after any activity that involves soiling of hands, for example, gardening. Learning by seeing others doing the same is most effective!

Daily Personal Care Routine

A daily personal care routine as suggested below, can usually be maintained with reminders, once it has been established. Despite some people with PWS becoming fixated with such a routine, the positive outcomes from making personal care a normal daily activity are beneficial for all concerned. If done properly, care routines can also provide a good opportunity to check for sores and infections resulting from skin picking, without confrontation. People with PWS often try to hide their skin picking so it is better not to overact or become upset if you do notice a sore or infection. Try to deal with it without showing any emotion. This way you may be able to discourage them from hiding these sores in the future. Early treatment with a bandaide and antiseptic can reduce the likelihood of infection.



To establish a daily personal care routine, set a time that suits the person with PWS and the household within which the person lives. Allow adequate time for the person with PWS to complete their care routine properly. This time should reduce once the routine is established, but may be lengthy at the start. Be aware of the requirements of others in the house when setting the personal care time!

Keeping Your Body Clean – to discuss with your person with PWS

- **Shower or Bath Daily:** Make sure that all areas are properly cleaned including; face; ears; neck; underarms; chest; back; bottom; legs; arms; between the buttocks; feet; between the toes and don't let them miss any of those hard to reach places. Use a liquid bath soap, soap, sponge and washcloth. It may require help or prompting in order to get the person with PWS to do this properly. An alarmed timer is handy to prevent prolonged washing, once the routine is established.
- **Wash hair 3-5 times a Week:** Brush hair daily and keep it tidy. Remember to wash or brush hair at the front, back, top and both sides of the head.
- **Clean teeth 2-3 Times a Day:** Learn how to “floss” as well and brush all teeth properly. One strategy is to encourage the person with PWS to pick a song that lasts a few minutes and keep brushing for as long as the song lasts.
- **Moisturise Daily:** People with PWS often benefit from moisturising once or twice a day. Particularly the feet, legs and any patches of dry skin.
Tip: moisturise with a sunblock cream!
- **Skin Check Daily:** Check all areas of their body for sores from skin picking. Use antiseptic and cover them up. Offer praise when there is no new sores but don't get upset if there are sores.
- **Clean Fingernails and Toenails Daily:** Keep them short and clean to avoid infections from scratching or skin picking.
- **Clothes:** Make sure that clothes are changed daily. Some people with PWS like to reuse yesterday's clothes. Make sure a routine is in place to put them all clothes in a clothes bin or wash them each day. Alert to wearing clean underwear and socks each day.
- **Wash Hands:** After going to the toilet, before eating and throughout the day, as needed.

A parent's suggestion:

People like my son had a good personal hygiene routine, however, is often left with an indication of what he has just eaten, around the outside of his mouth. I always carry “wet wipes” or similar moist tissues to clean on the go. A comb and spare bandaids are also always carried in my bag!



Strategies That Help

- Routines that are practiced daily at set times. Never let personal care be missed even for a day. People with PWS will generally follow a set routine but may easily slip out of personal care routine.
- Plenty of praise and positive feedback. Encourage taking pride in being clean and smelling fresh.
- A visual chart can be placed on the wall that shows the time it takes to get ready to leave in the morning or for bed at night. Having a routine with each step that needs to be completed to be ready on time, with a timeframe can be useful.
- Having supper or breakfast only after the personal care routine completed is a good way to make sure it is completed.
- Set regular days for washing clothes. Count the amount of each item that is there to be washed e.g. if you wash once a week there should be 7 pairs for socks to hang out on the line.
- In hot weather allow the feet to breath, encourage them to wear thongs or sandals around the house.
- Remind the person with PWS to dress similarly to you, according to the weather! Less clothes when it is warm and more clothes when it is cold. Heavy clothes in hot weather does not help hygiene!
- Instead of saying you are applying moisturising say you are giving them a massage. This can also improve circulation especially for diabetics.
- Encourage and praise good manners. Make sure that you apply personal care rules to everyone that lives in your house. That way it is not just targeted at the person with PWS.
- Set a good example and let the person with PWS know that you are washing your hands before meals and that you brush your teeth every day.

