

Being Part Of The Process: A Caregiver's Perspective

By Laura Dann and Janet L Kuhnke, RN BA BScN MSc NSWOC Dr Psychology

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Introduction

One of the commitments at Wounds Canada is to prioritize and engage the voice and stories of patients and their families. In recent months, and as part of the pending updates to the *Best Practice Recommendations* (BPR), several caregivers were approached to be part of the process.

In January 2023, Laura Dann, a primary caregiver and care manager for her son AC, was approached to be part of the process of updating the *Prevention and Management of Moisture-associated Skin Damage* chapter. As part of the team process, we met several times to discuss the process, access the documents, and to explain expectations. Laura had previously published a *Wound Care Sleuth* focused on health care and families coming together to create patient-centered plans of care. Her involvement in the *BPR Update* was important to her as she daily coordinates a team of support workers to promote skin

health and provide total care for her son, an adult living at home and requiring full time support.

Laura Shares Her Perspective

My initial response when asked if I would be interested in being part of updating a best practice recommendation on skin health was one of curiosity. I was interested as I did not know that such a resource existed for patients and their families. Yet, after publishing in *Wound Care Canada* in the fall of 2022, I learned that there was skin, wound and continence expertise available in the community of which I did not know about.

I am a care manager for my 35-year-old son, AC. He has worn briefs



Laura Dann

full-time for both urine and bowel incontinence his whole life. Throughout this journey, I had often come across the need for skin care routines, yet nothing was readily available or known to me. When I needed information, I researched online, spoke to valued support workers and people on his interdisciplinary team and, most often, used a 'trial and error' approach. As well, I have two sisters that are registered nurses, and we often brainstormed ideas to consider, knowing, in the end, it was my responsibility to ensure his skin was healthy.

Joining the team for the *Moisture-associated Skin Damage (MASD)* chapter of the *BPR Update* was of great interest. I was motivated to read and learn about the complexity of protecting skin, promoting hydration and choosing briefs. We met regularly on Zoom and benefitted from some expert guidance and input. The process was very much a team effort, and the authors wish to acknowledge the leadership of Louise Forest-Lalande, the chapter lead.

The Dance Of Skin Hydration

This MASD project was important to me as AC, who is challenged by an intractable seizure disorder and an acquired brain injury that affects every aspect of his life, was struggling with his skin related to urine and bowel incontinence and his hydration. AC is cared for at home with 24-hour care.

Knowledge Of Nutrition And Hydration Improved

From 2018 to 2020, we as a team supporting AC, were challenged to find a nutrition plan that might help reduce his seizure activity. One of the suggestions (January 2020) from his long-term neurologist, was to start AC on the Keto food plan. At the same time, she also referred me to a second neurologist specializing in Keto diets and epilepsy management. This plan was in place until 2022, when we waited for the first neurologist to make a referral to a Registered Dietician (RD). I was hoping this would be a good resource for me and the team.

The RD offered general guidance. The challenge

we experienced was that the RD was at a disadvantage trying to balance the variables of AC's complex neurological condition, an intractable seizure disorder, incontinence (urine and feces) and managing a food plan that all had to work seamlessly. While his diet was discussed specific to fat, carbohydrates and protein grams, his hydration was not reviewed or discussed. In February 2023, I met again with the neurologist specializing in Keto. Again, hydration was not a priority. Later, and in discussion with my sister, we wondered if his recovery from a seizure was longer if he was dehydrated as he often would not drink fluids for some hours after the event.

As a result, we implemented a hydration plan including offering him a drink every thirty minutes during his seizure recovery hours and days. Ongoing, our goal is to ensure he drinks 36 to 48 ounces of fluid a day. One of the things I learned being part of the MASD team is the importance of oral hydration to improve his urine output and bowel health and the overall health of his skin. We observed the changes within a week of increasing his oral hydration. His communication abilities appear to be more interactive and more responsive. His pale and often colourless skin has changed to clearer with a rosy colour. His urine output changed from an odourous dark yellow to pale in colour with less odour. While his bowel movements did not change, we know the added hydration is helpful as AC takes additional fibre tablets two times daily.

Learning Moments:

- Hydration is essential for skin health
- Prevention of moisture-associated skin damage is a team effort
- Poor fitting briefs can create skin damage
- Observe, listen, and continue to learn when your loved one cannot speak for themselves.
- Ask for referral to a wound care clinician or nurse specialist in wound, ostomy and continence.

Knowledge Of Briefs Improved

Over the past years, choosing briefs and fitting them was just a 'guess'. While I have used many name brand products and some store-brands for AC, it was about availability and fit next to his skin. When choosing bed pads, I usually opted for washable pads for breathability and their ability to stay in place on AC's bed when he moves throughout the night, and to reduce waste and cost. Later in his early adult years (age 19-20) I was introduced to a moisture barrier skin cream. I still use the same cream today, 17 years later.

During the process of updating the MASD best practice recommendation, I learned about the role of a Nurse Specialized in Wound, Ostomy, and Continence care (NSWOC). This filled a void on his care team and will be a well-respected resource. Two years ago, he had experienced a serious skin breakdown from excessive urine and feces contact on his skin. It took 4-5 months to resolve the skin issue using trial and error. As a care manager, I had no one to discuss skin cleansing, continence products used/how to fit them, creams available/used, healthy skin condition and what families should look for to be proactive to avoid skin breakdown. It would have been so helpful to have known about what an NSWOC could offer in guidance and recommendations to resolve this skin breakdown in less time.

Final Notes

I believe each patient who wears briefs constantly and is at risk for moisture-associated skin damage should have an automatic referral made to an advanced wound clinician or a NSWOC nurse for an annual, or as needed, consultation. Families and care managers like myself should be aware of the resource of the *Prevention and Management of Moisture-associated Skin Damage* chapter. Having this knowledge would encourage families to act before a skin inflammation or breakdown occurs.

As an avid reader, I believe that a pamphlet in each doctor's office would benefit caregivers and families describing support available and offering families a website link and a phone number to call for information. On retail websites and

manufacturers of continence products, I believe it is incumbent on the large manufacturers to offer skin care information, on their websites and/or with an insert in the packaging. For local shopping, I would like to see a pamphlet given with each purchase explaining what healthy skin is, what moisture-associated skin damage is and what to look for.

Thank you for this opportunity. It is important that Wounds Canada continue to involve families and their loved ones in education. 🇨🇦

Laura Dann is the primary caregiver and care manager for AC, her 35-year-old son.

Janet L. Kuhnke, RN BA BScN MSc NSWOC Dr Psychology is Associate Professor in the School of Nursing, Cape Breton University, Sydney, NS.



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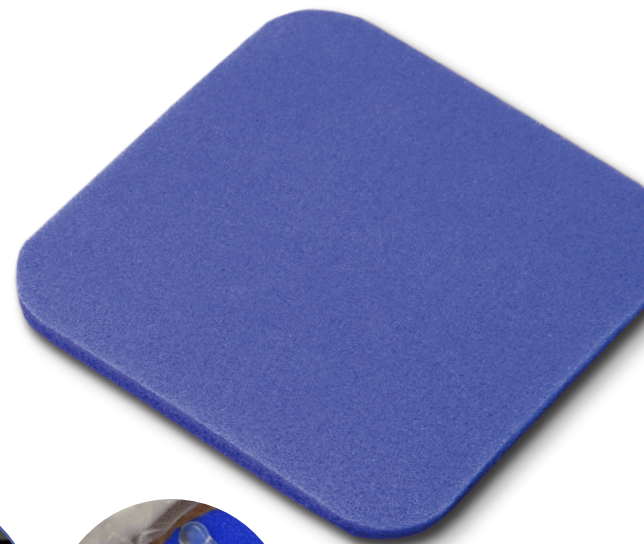
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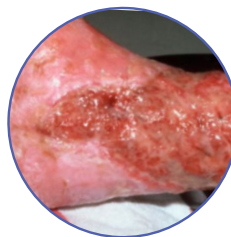
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