



Passing on the Scale:
Transitioning an Infant with PKU into Licensed Childcare
By Laura Demchuk Sloan, PhD

As the months of my second Maternity Leave faded away, my anxiety about handing over some responsibility for my baby's PKU to others increased. It was alleviated somewhat by the fact that I knew most of the staff at the daycare she would be attending, since my older daughter (non-PKU) had been in their care for the previous 3 years. Yet, I knew I had to develop a plan for how we were all going to manage this next phase in my baby's life with PKU. At 11 months of age, she began transitioning into the infant room at our daycare. Here is what I did to help us and the daycare successfully navigate PKU and keep her healthy. Please feel free to use and/or adapt any of the following ideas, if you have a young child entering childcare:

- 1) Since we had been a family at that daycare for many years, the staff and Executive Director knew of the PKU diagnosis since the beginning. Periodically, I would check in with the Executive Director (ED) regarding her start date and our potential transitioning plan before she started at the daycare.
- 2) The first thing we decided would be helpful was a presentation to the staff – this occurred at a staff meeting a few weeks before her entry to the infant room. Please see “PKU daycare presentation” for the presentation notes that I used to guide my talk. Some information came from other sources. It is not in Power Point form, but could easily be converted to Power Point. I also had a 1-page handout, summarizing the main points.
- 3) At this presentation, I brought many visual and hands-on materials, including:
 - Phenex formula can
 - Non-perishable food samples, such as boxes of pasta, Crackles, Macaroni and Cheese
 - Heel prick test papers and lancet
 - Sample daily food record sheets
 - Digital scale, measuring cups and spoons

It should be noted that I had very positive feedback from many of the staff about the presentation, including those in other programs (e.g., preschool).

- 4) The daycare purchased their own digital scale, measuring cups and spoons (and these have followed her into each new program).



- 5) I consulted with the PKU clinic dietician, who suggested that I develop and give the daycare staff a “green-yellow-red” food list for prominent posting in the infant room. I tried to print in coloured ink or printed on coloured paper for ease of reference. See “green-yellow-red food list” for my chart; of course, you will need to adapt it to your own child and his/her PKU clinic’s recommendations.
- 6) I spent the first few days of her transition with her in the infant room. At this point, I was able to share further information with the infant caregivers regarding PKU and her diet management. In addition, I was able to spend her first few lunches showing the caregivers how to use the scale etc. and I was able to observe them.
- 7) I was always easily available via phone the first few weeks for any questions or concerns. I am still available each day, for any questions or problems.
- 8) I used the daycare lunch (prepared by a catering company) and snack 4-week rotation menu to develop a similar 4-week menu plan for my child. I incorporated as many menu items as possible and tried to substitute similar low protein items whenever possible. See “infant sample meal plan” for a one of these menus.
- 9) I would look at the upcoming menu for the week each Sunday night (and still do), and would update it according to any changes to her daily equivalent (exchange) goal, any menu changes from the catering company (e.g., change from Winter to Summer menu), and my child’s own likes and dislikes (which frequently change!).
- 10) I would write update notes every few weeks while she was in the infant room regarding formula changes (daily amounts or the formulation), her Phe level, vitamin changes (e.g., iron supplementation), and her growth. They seemed to appreciate being kept informed about her health and progress, especially after clinic visits. I do not write these notes often now, only after clinic visits or major diet changes.
- 11) At 19 months of age, she transitioned into the Toddler room at the daycare and the procedure was very similar with regard to educating the staff. The toddler menus are different and I decided to add information about the equivalent amounts of each food so that her caregivers might understand some of the decisions I make about amounts and choices of foods. Please see “sample toddler meal plan” for an example of such a menu. You will notice that I use various colours for different information, to make it more readable for the staff.
- 12) I have ensured that they have a PKU food list available to them which contains weights of vegetables per equivalent, as a back-up reference in case of last-minute menu changes.
- 13) I have contacted the catering companies (there have been 2) regarding sending substitutions for some menu items (e.g., sending plain carrots if it is a day when



the rest of the children are eating a stew with meat and vegetables mixed together). I have to say, however, that the catering companies are much less reliable than the daycare caregivers, and frequently proper substitutions are not sent. This is something we are constantly working on.

14) I leave packages of low protein bread in the daycare freezer and they let me know when I need to supply more. I leave other non-perishable low protein food (cereal, cookies) in their cupboards and they have purchased other back-up items (pudding cups, fruit cups, etc.).

15) Every Monday, I bring that week's menu to the daycare and they post it prominently. A blank food record is copied on the other side of the "infant/toddler daily report" – we and the daycare staff use this food record to make note of what she has eaten and how much, as well as her formula amounts.

16) We have a copy of the week's menu on our fridge and look each night to see what we need to bring the next day.

17) Finally, I have made it very clear that supply daycare staff who have not been trained regarding her condition, are not to have any responsibility toward feeding her. Fortunately, enough staff from both the toddler and infant room (6) are properly trained, so this has rarely been a problem.

To conclude, I have to say that everything has worked amazingly well this past 16 months and that I have very few complaints or concerns. If there are any problems, we correct them immediately. Although the daycare caregivers were initially apprehensive about her condition, they now feel confident and empowered that they can successfully care for her diet needs. As much as possible, we try to express our appreciation to them for helping us keep her healthy, happy, and growing.

Disclaimer

The information provided here is intended for informational and educational purposes only and in no way should be taken to be the provision or practice of medical, nursing or professional health-care advice or services. This information should not be considered complete or exhaustive and should not be used in place of the visit, call, consultation or advice of your physician or other health-care provider. You should not use the information on this website or any Canadian PKU and Allied Disorders Inc. communication to diagnose or treat PKU or any other disorder without first consulting with your physician or healthcare provider. Any referral to physicians is provided as a courtesy only.