



## Prader-Willi Homes of Oconomowoc Respite Care Informational Guide

The information included in this guide may answer a few of the questions you have about our Respite Care program. If you have additional questions, please contact your admissions representative.

### **How long can my child visit?**

A respite visit can be as short as a couple of hours to as long as 9 days for a child under the age of 18 and up to 28 days for an adult. If a visitor or family is interested in having another visit, there needs to be a minimum of 24 hours in between visits.

### **What will my child's visit consist of?**

Visitors will follow the same daily routine as the other individuals in the home; including everyone's favorite... fun activities and community outings. Children will have the opportunity to participate in the Day RISE program as well as those adults visiting during weekdays. Depending on the length of the visit and the visitor's preference, they may be able to go to work and earn a paycheck with the rest of the individuals in the home. Visitors will be encouraged to shower, as well as participate in exercise daily. See the questions below pertaining to diet and activities for more information about the daily schedule.

### **What should my child bring with them when they come for a visit?**

It is best to think of it like packing for a vacation. Visitors will have access to laundry facilities at the home, limiting the need for excessive clothing to be packed. In order to assist, we have provided a list of recommended items. Please see below.

Please label all items with the visitor's initials. An inventory of the items brought will be taken upon arrival and reviewed again prior to the visitor leaving. This will help to ensure that all of their belongings are present and that all of the items being sent home belong to the visitor.

We ask that items of particular value are left at home during the visit to prevent the item from being lost, damaged, or stolen. PWHO is not responsible for lost, damaged or stolen items.

We also ask that no food, gum, candy, flavored water or other items that are edible are brought with or sent to the home.

Suggested items to be brought for a visit:

1-3 Days	4-7 Days	8-28 Days
<p><b>Clothing:</b>            4 Pairs of Underwear            2 Bra's (if applicable)            4 pairs of socks            1 weather appropriate outfit for each day to include a top and a bottom            1 weather appropriate jacket            1-2 pairs of pajamas            1 pair of sweat or exercise pants            1 extra T-shirt            1 pair of slippers(optional)            1 pair of Tennis Shoes or Sneakers            1 Robe (optional)</p> <p><b>Personal Items:</b>            Prescribed medications (enough for each day)            Over the counter medications in original packaging            Hygiene products: 1 of each product            Eye glasses (if applicable)            Hair accessories            1 puzzle/activity/coloring book            2 pens/pencils            2 DVD's            1 board game to play/share with friends            1 doll or stuffed animal            Spending Money (see below)</p>	<p><b>Clothing:</b>            7 Pairs of Underwear            3 Bra's (if applicable)            7 pairs of socks            1 weather appropriate outfit for each day to include a top and a bottom            1 weather appropriate jacket            1-2 pairs of pajamas            2 pair of sweat or exercise pants            3 extra T-shirt            1 pair of slippers(optional)            1 pair of Tennis Shoes or Sneakers            1 Robe (optional)</p> <p><b>Personal Items:</b>            Prescribed medications (enough for each day)            Over the counter medications in original packaging            Hygiene products: 1 of each product            Eye glasses (if applicable)            Hair accessories            2 puzzle/activity/coloring book            3 pens/pencils            3 DVD's            1 board game to play/share with friends            1 doll or stuffed animal            Spending Money (see below)</p>	<p><b>Clothing:</b>            7-10 Pairs of Underwear            3 Bra's (if applicable)            7-10 pairs of socks            7-10 weather appropriate outfit for each day to include a top and a bottom            1 weather appropriate jacket            1-3 pairs of pajamas            3 pair of sweat or exercise pants            3 extra T-shirt            1 pair of slippers(optional)            1-2 pair of Tennis Shoes or Sneakers            1 Robe (optional)</p> <p><b>Personal Items:</b>            Prescribed medications (enough for each day)            Over the counter medications in original packaging            Hygiene products: 1 of each product            Laundry detergent/fabric softener            Eye glasses (if applicable)            Hair accessories            5 puzzle/activity/coloring book            5 pens/pencils            5 DVD's            2-3 board game to play/share with friends            1 doll or stuffed animal            Spending Money (see below)</p>

Depending on the time of the year, additional items may be needed: swim suit, beach towel, dress clothes, winter boots, hat, mitten/gloves, and scarf.

If your child would like to bring an item that is not listed, please contact your admissions representative.

**What will my child already have in his/her bedroom?**

While visiting, your child will have a private bedroom to stay in. The visitor's room will have a bed (with linens and a pillow,) a dresser, a hamper, and trash receptacle. The room will also have a television with a DVD player so that they may watch movies if they would like to.

## **How is my child's diet determined and what will it consist of?**

Based on the information that is collected prior to the visit, PWHO will review what the visitor's current caloric intake is and implement a comparable meal plan. The meal plan can be modified to meet the visitor's specific needs, especially if weight loss is a goal during the visit. The PWHO dietician reviews the house menus to ensure that a wide variety of healthy and nutritious meals are being served. All individuals receive three meals a day, breakfast, lunch, and dinner. They also receive a healthy snack during the day and a low calorie treat in the evening. Accommodations for individuals with other dietary needs will be made based on written documentation from a medical professional, (i.e. food allergies, diabetes, lactose intolerance, etc). Due to the food seeking behaviors inherent of the syndrome, environment supports, such as locked refrigerators, freezers, and all food cupboards, are used to ensure an individual's health, safety, and well-being.

## **What activities are planned for my child to participate in?**

Each home has a monthly activity calendar that is pre-approved by the administrative team. Visitors will have the opportunity to participate in all of the activities that are planned during the duration of their visit. Activities are planned daily with a vast variety of options, while taking into consideration the interests of the individuals who reside within the home, the affordability of the activities, and the appropriate community integration skills displayed by the individuals for the activity. The calendars are posted within each home for the individuals to refer to at their leisure. If the planned activity is postponed due to weather or health and safety reasons, all attempts to reschedule the activity will be made. All in-house and community integrated activities are optional although every attempt is made to encourage active participation. If a visitor would choose not to participate, they may be asked to visit another home during that time so that the other individuals in the home are still able to participate.

## **Should I bring spending money for my child?**

Each individual who visits PWHO for Respite Care may have a "Cash on Hand" account set up within the program to be used for activity spending. This account would be established by funds provided by the individual/parent/guardian upon the beginning of their visit. We recommend that approximately \$20-\$30 per week is provided for your child for activities and/or personal shopping. This recommendation may change depending on what activities are planned during the time of the visit. An assigned staff member will handle the visitor's personal funds and will assist with budgeting and money management. All funds will be kept secured to ensure safety from accessibility. All funds not spent while on the visit will be sent home as well as a detailed account and receipts of all transactions made during the visit.

## **When is it ok to make phone calls?**

Maintaining contact and involvement with your child is strongly encouraged. Each home has a separate phone line for the residents/visitors and designated times built into the daily routine for phone call use. (Typical between 4pm-9pm CST weekdays, 9am – 9pm on the weekends) It is important for family members to understand that the resident line is shared by all of the residents within the home, and that there may be time limits set by the support staff to ensure that everyone is afforded an opportunity to talk with their loved ones.

Due to the needs of the individuals that we support, all staff is needed to ensure the safety and wellbeing of the individuals in the home. Staff members are trained not to take phone calls while they are supporting residents. Often times a phone call requires a staff member to step out of coverage to tend to the call. If family members have any questions or concerns please contact your admissions representative or the house management team.

### **Can my child bring and use their personal electronic devices?**

Visitors may choose to bring their cell phone and/or lap top computer for use within the home at their own discretion. PWHO is not responsible for lost, damaged or stolen items. Wi-Fi is not provided in the home. If misuse of the computer, cell phone or internet occurs, it will be evaluated whether further use will be permitted.

Personal electronic devices are not permitted at DayRISE or work locations.

### **What if my child becomes sick while visiting?**

If a visitor experiences signs of illness or a non-emergency medical concern lasting a period of 48 hours, the guardian or emergency designee will be contacted and asked to come and pick them up. We ask that they be picked up within 24 hours of being notified. Prior to the visit, permission is granted for staff to contact the visitor's primary physician to discuss and seek direction regarding any medical concerns. Routine medical appointments such as general doctor visits, OT, PT, etc. are outside the scope of care we provide for our respite program and will need to be done prior to or after visiting. If the primary physician is contacted for a medical concern and recommendations for treatment beyond our scope of care is made, the guardian or emergency designee will be contacted. In the event of an emergency or a serious medical concern requiring immediate attention, PWHO staff will contact the guardian or emergency designee and inform them of the situation. PWHO staff will accompany the visitor to the hospital and remain with them until the guardian or designee arrives and takes over medical responsibility. Visitors will need to be deemed healthy and medically stable by a medical professional prior to returning to the home and continuing their visit.

### **What if my child wants to become involved with a dating relationship?**

PWHO encourages positive relationships between all individuals who reside within the homes. Individual's living or visiting here and are strongly discouraged from dating someone living within the same home. If your child is interested in dating an individual living at a different home, please bring it to the attention of your admissions representative for fuller discussion.

### **What are some of the techniques used to manage challenging behaviors?**

Structured, motivational and behavioral support is an integral part of our program. This is a primary competency of PWHO. Our goal is to assist each of our residents in appropriate pro-social behaviors, fostering and supporting such behaviors, and offering choices designed to enhance successful community living.

Although it is our objective to develop an individual's ability to respond appropriately through personal communications, actions and interactions, at times it may be difficult due to the challenging behaviors associated with the syndrome and other possible related mental health issues. A person diagnosed with Prader-Willi syndrome may at times experience a lack of emotional control, and in these situations the individual no longer has the ability to make safe decisions for themselves. If dangerous behaviors occur, the use of physical interventions may be utilized as a last resort to ensure the visitors safety as well as the safety of others. Through the use of the Pre-Respite Care Assessment process, proactive approaches are developed and a Respite Care Plan is created. This plan addresses the visitor's needs and utilizes their strengths and their interests, as well as other motivating factors.

The first and foremost responsibility of our staff is to provide a safe and therapeutic environment, where individuals are given the necessary time to demonstrate the ability to interact on an acceptable social level as well as to ensure their individual safety and the safety of others. If the visitor experiences a lack of

emotional control or has displayed disruptive or unsafe behaviors, the support staff will assess whether community activities would be appropriate or in the best interest of the visitor at that time.

**Who should you call if you have any questions, comments, or concerns?**

Your admissions representative is the primary source for contact. If questions or concerns arise, they should be contacted and they will address the concerns with the appropriate team members. In addition, the Home Management Team is available in the event of an emergency.

*PWHO would like to make every family feel welcomed and part of our “Homes with a Heart”. We hope the above information is helpful and may serve as a useful tool in making this visit as smooth and as comfortable for your child. Please feel free to contact us if you have further questions.*