

Frequently Asked Questions about the RND Program *At The Children's Hospital of Philadelphia*

General Questions:

1. Q: Why can't parents be present for therapy?
A: *During the day, we want your child to be able to concentrate on getting better. Often when parents are present during therapy, patients have a more difficult time pushing through their activities*
2. Q: Can I eat lunch with my child?
A: *For the first week, we do allow parents to have lunch with their child. By the second week however, it is not allowed. This is so they can have lunch with their peers which will more closely mimic a school day, which assists with their transition back to school..*
3. Q: Can my child carry their cell phone to therapy?
A: *This is strongly discouraged. If they do need to bring their phone in order to arrange pick up at the end of the day, it should be turned off for the time they are in therapy. Otherwise it should stay at home. It is distracting not only to their therapy, but also for those around them if their phone is ringing during therapy. Also, phone calls are not permitted to be made during therapy sessions as to not interrupt your child's progress.*
4. Q: What should my child do in the evening?
A: *Patients should go to bed at a normal time. They should not go to bed early during the program to "rest up" for the next day. Regardless of whether your child is inpatient or day hospital, they should stay active throughout the evening.*
5. Q: My child woke up sick. Should I still bring them in?
A: *Unless your child has a fever over 101 degrees F (38.3 degrees C), they should come into the program. Dr. Sherry, the other physicians, or nurse practitioner can check you child and obtain any necessary testing or prescribe medication if indicated. If they are too sick or contagious to participate for the day he or she will be sent home. Most children, however, can participate in the program when they are ill and the program is modified accordingly. In many cases, symptoms which mimic illness such as headache, dizziness, nausea, vomiting and diarrhea go hand in hand with RND and it is important for your child to work through these symptoms. This will help train their body to decrease his or her symptoms and for them to learn to function, including going to school, despite these symptoms.*
6. Q: How long will the program be?
A: *This is individualized, but the average is 2-4 weeks.*
7. Q: When will I find out about progress/discharge?
A: *Although the team is in daily contact with each other, on Thursday's, they meet formally to discuss the progress of the patients in the program and their plan of care.*
8. Q: What if my child or I don't feel as though they are ready for discharge when the team things they are?
A: *It is not uncommon for parents and patients to be nervous around discharge, especially if they are not pain free, but sometimes discharge from the program is essential to continuing to improve as for some patients many more gains are seen once they return to their normal activities. See question number 10 below for more information*

on this. The decision to discharge a patient from the program is not entered into lightly, and many factors are weighed and discussed by the team prior to deciding on a discharge date.

9. Q: What is expected of my child once they are discharged from the program?
A: At time of discharge, your child will be provided with recommendations specific to their needs. In general, they receive a home exercise program similar to their weekend program and are expected to return to school full time. It is also generally recommended that patients return to previous sports and or clubs they enjoy.
10. Q: When will the pain go away?
A: There are 3 parts of the program. Part 1 is the intense, 5 hours a day, physical and occupational therapy. Most children regain their function during this part. Initially, the pain may increase and most will have muscle soreness from doing so many exercises. By the end of part 1, most children will start to have a decrease in their pain and in some, the pain will go away. For most children then reduction in pain is gradual but it can suddenly stop. Part 2 of the program is going home, maintaining normal function (going to school, chores, sports, social activities), doing a home exercise program (about 45 minutes a day) and, for most, going to counseling. It is during the second part that the pain will go away for most children. Part 3 is getting to the point that they do not need to do a home exercise program but just have normal activities without having any pain.
11. Q: Can the pain get worse or spread?
A: Yes. Besides the muscle soreness, it is common for the RND pain to get worse once we start doing a lot of exercises using that body part. The RND pain can also spread to different locations. This is generally regarded as a good sign since we seem to be connecting to the nerves leading to the amplified pain and it occurs frequently as the RND pain starts to get better.
12. Q: Will my child's RND ever reoccur?
A: Every patient is individualized, and so is their recovery. An important part of the program is teaching each patient the skills they need to be able to manage their own health and overall wellbeing. This includes what they should do if they should ever think their RND is reoccurring. In one study, after 5 years, it reoccurred in only 30% and half of these children could work out the RND without having to return to the RND program. Half of the children who have a recurrence say that the pain feels the same and half say that it feels different and cannot be RND. Important clues are when the pain seems to hurt too much for the injury or illness, is prolonged past the time that normal healing should have occurred, or the skin is tender to light touch. RND pain causes more disability than one would normally expect. If any of these clues occur, your child should start to exercise, use that part of the body in a normal fashion, desensitize if it is tender to touch, and think about what stresses are going on in his or her life.

Inpatient Questions:

13. Q: Can I stay over in the hospital if my child is inpatient?
A: In order to foster independence, we do not allow parents to stay overnight when patients are inpatient in the RND program.
14. Q: What should my child do in the evening?
A: For inpatients if parents are visiting in the evening, they can get cafeteria vouchers for their dinner. The Connelly Center on the 8th floor of the main building has internet

access, washing facilities, as well as book and movie libraries. When the weather is nice, you can also sit out in front of the Seashore House building in the park area or go out on the play deck on the 3rd floor. If no adults are visiting in the evening, patients are encouraged to socialize with other patients on the unit, or make use of the playroom. There is a TV there with video games, a computer with internet access, and a variety of other games/activities available. The family lounge also has a TV and internet access.

15. Q: Are all meals supplied for inpatients?

A: Yes. Breakfast, lunch and dinner are supplied. There are also some snacks and drinks in the pantry on the unit that your child may have. In the evening, when parents are visiting, patients can also request to their nurse to have a cafeteria voucher instead of having dinner delivered to the room. This gives them time off the unit and a chance for a more varied meal.

16. Q: If my child is inpatient, what does he/she do on the weekend?

A: As an inpatient, your child will receive 45 minutes each of physical and occupational therapy each day over the weekend. They will also receive a home exercise program to perform in their room each day. They should also stay active through going for walks in the hospital, over to the Connelly Center, etc.

17. Q: If my child is inpatient, can they go out over the weekend?

A: This is individualized, but there are often instances where we will encourage parents to take their child out on a pass on Saturday or Sunday or both to practice skills learned during the week out in the community.

Day Hospital Questions:

18. Q: Is lunch supplied or does my child need to bring lunch?

A: For day hospital patients, lunch is provided as part of their day at no additional cost.

19. Q: What should my child do in the evening?

A: For day hospital patients, it is recommended to go out and see the city, etc in the evenings if staying at Ronald McDonald house or other places in the city. If they are coming home, they should keep up with peers and other family activities they typically do in the evening.

20. Q: What should my child do on the weekend if they are in the day hospital program?

A: They will have a home exercise program to perform twice each day. Also, we recommend they do something fun with peers. We strongly encourage patients to remain active over the weekend to foster continued progress over the coming week.

Therapy Questions:

21. Q: What are some of the exercises that my child will do?

A: The exercises are individualized according to the needs of each child. However, there are some that are generally used in most children such as tub step in (stepping in and out of tub repeatedly in 1 minute), animal walks (inchworm, frog, duck, crab, and 3-legged puppy), leg and arm step-ups (stepping up a step and down 40 times), box carry (picking up a box, carrying it 3 feet, setting it down and repeating this for a certain distance) walking on the treadmill, and various forms of desensitization including rubbing, vibration, and patting. Many of these are timed and the child will be expected to beat their times each day until they reach their maximum speed.

22. Q: Will my child get pool therapy every day?

A: In most cases, not every day. Pool therapy is definitely an important part of the treatment, but most patients will not benefit from receiving it every day. How much pool therapy each patient gets is individualized depending on many factors. Those factors include, but are not limited to presence/absence of allodynia, muscle soreness, sport specific training for swimmers, and performance during land therapy and sometimes in conjunction with behavioral programs. It is best for each patient to bring their swimsuit each day so they are prepared for the possibility of pool therapy. We will make every effort to incorporate pool therapy whenever possible and appropriate to your child's care.

23. Q: What if my child declines to participate in certain therapy activities?

A: Behavior modification programs are sometimes utilized to help your child meet his/her treatment goals. Behavior modification programs will be individualized to meet your child's needs. Typically, privileges (i.e., MP3 players, TV time, Computer time, opportunity for fun activities, visitation time, etc.) will be earned when your child completes his/her goals. Your child may be required to stay after 4 pm to reach goals and may lose privileges if goals are not met. The psychologist is typically involved in helping your child understand this program and identify strategies to help meet goals.

24. Q: What if my child declines to participate in all activities?

A: An occasional child cannot force themselves to participate because of severe depression or due to oppositional behavior. In these cases, we have referred him or her to an appropriate mental health provider. This is always done with a lot of thought on part of the team, child and family. We try to work with the child, generally for several days before any final decisions are made concerning the appropriateness of our program. If the child is released, once the psychological issues are addressed then he or she may return to the program, if it is still needed.

25. Q: What do I do if my child has a lot of pain at night after exercising in the program?

A: They may be sore in the evening after completing exercise, but they should continue to stay active in the evening. Resting for a few minutes right after the program is fine, but then activity is best. They should also stretch in order to keep muscles from tightening up. Other than that, just staying active as stated in the above answer is the best thing.

26. Q: Should I remind them to do their home exercise program?

A: In most cases, no. We encourage the patient to take ownership of their recovery, which includes performing their home exercise program independently.

27. Q: My child says the therapists yell at them. What is that all about?

A: The physical and occupational therapists have worked with many children with RND and generally have a good idea of what the child can and cannot do. Frequently the child will think that the goals are too hard. The therapists have to be stern at times but do not yell at the child. They will act as cheerleaders to encourage them and that can be interpreted as yelling (i.e., "Go, go, go – you can do this, go faster! You can beat this time!"). Everyone on the team is dedicated to providing the best of care in a caring and sensitive way but many children procrastinate or "cheat" by avoiding normal form or function and need verbal reminders to correct their form or get started on the next activity. This may be interpreted by the child as chastisement.

28. Q: What do I do if I think something is not appropriate?

A: Please contact either Dr. Sherry, the attending physician if Dr. Sherry is not in town, or the nurse practitioner and discuss your concerns. It is best to deal with these situations

early on rather than let them fester. Remember, a man's story sounds good until you listen to his neighbor – every story has more than one side.

Psychology Questions:

29. Q: How can/does stress make pain worse?

A: Many people keep painful feelings (such as sadness, worry, feeling overwhelmed) inside, but for some, these feelings need a way to be expressed, and sometimes are expressed as physical symptoms, including pain. Stress comes in a variety of forms. Sometimes stress is a “big event,” sometimes it comes from difficulties in school or in the family, and sometimes it comes from managing many different (often enjoyable) activities and we are not even aware that we are stressed. Physiologically, the body does not care from where stress comes, but reacts the same way. When faced with stress, our bodies prepare to fight, flight, or freeze, as a way to deal with the stress. This response is a way to avoid physical threats (e.g., a tiger chasing you), and allows your body to survive against the threat. Unfortunately, our bodies cannot tell the difference between physical threats, such as a tiger, and psychological threats, such as an important test at school. If we sense a threat for whatever reason, several changes occur in the body, including an increase in heart rate, increase in breathing rate, changes in hormones, tightening of muscles, increased blood flow to muscles and away from skin, increased perspiration, hypervigilance to the environment, etc. These responses enable us to survive in the immediate future in the face of threats, enabling our muscles to be stronger, our bodies to cool and be slippery, our bodies to not bleed to death if injured, our minds to be more away of other potential dangers, etc., but leave us vulnerable to other threats, such as pain due to muscle tightening, increased blood pressure, and imbalances in hormone levels. Pain can be a cause of stress and stress can cause pain to become worse and/or to persist. Dealing with stress helps decrease the impact of stress on pain.

30. Q: How does talking make pain better?

A: Talking can make pain better in several ways. First, talking provides a way to understand how stress and pain are related. Exploration of stressors and discussion of ways to help identify and reduce the impact of stress can help decrease the impact of stress on pain. Additionally, talking about coping mechanisms (e.g., deep breathing, visualization, distraction and other cognitive strategies) that one can utilize when experiencing pain can help decrease pain.

31. Q: My child does well in everything...what could they be stressed about?

A: Stress does not only come from “negative” experiences or situations. Some of the most stressful times in our lives occur when we are happy and doing well, and often occur during times of change. Many people experience stress by trying to manage several different activities at one time. This can be even more challenging when you like and are good at all of these activities and have difficulty prioritizing these areas of your life. What ends up happening for many people is that we are very busy enjoying so many things and feel pressure to continue succeeding at each. This can be stressful, especially for people who have tendencies toward perfectionism.

32. Q: Why do you need to talk to their psychologist or psychiatrist?

A: It is important for us to work in conjunction with other professionals, including psychologists, treating your child so that messages are consistent and recommendations are feasible and able to be supported after leaving the program. We have a very limited

amount of time to learn a lot about your child and your family, so being able to consult with other professionals who have had contact with you can be very helpful for us to be able to provide you with the best care. It is also helpful for us to consult with other professionals to share our expertise and to make recommendations for discharge in order to help these professionals best support continued healing.

33. Q: This is my child's pain. Why are you recommending family therapy?

A: As part of normal development, children grow and become increasingly independent from their parents and other family members. Adolescence becomes a time of experimentation and rebellion, much of which is normal and healthy. Parents of medically ill children (i.e., children in pain) may become more and more protective as the children grow, which can lead to struggles with individuation and independence. Additionally, other stressors between relationships with siblings and parents, and relationships between parents, can also be sources of stress that may serve a role in causing and/or maintaining pain. Family therapy is often recommended to further assess family dynamics and relationships and help provide guidance about how to help the family function in such a way that all family members experience less tension. Because of the way that stress impacts the body, a reduction of family stress can help decrease children's pain.

34. Q: If I don't ask about my child's pain, he or she will think I don't care. How is that helpful?

A: Research shows that attention to pain (e.g., asking how your child is feeling, asking what the pain feels like, saying you hope your child feels better) actually makes pain worse. Instead, pain tends to decrease when parents respond to children by distracting their attention to others things (e.g., activities, discussion about things other than pain). It is important to let your child know that you care about him or her and that you want him or her to feel better, but that you will no longer ask about or respond to complaints of RND pain because you know it is in your child's best interest to help him or her refocus on something other than pain.

School Questions:

35. Q: Will my child receive school or tutoring while in the program?

A: No, your child will not receive school services while in the program because of the intensity of the therapy schedule. However, the Education Coordinator is available to your child if there are questions about specific assignments. If needed, assignments can be faxed to your child through the education department. Also, the Education Coordinator can make a computer available during lunch or breaks in the day to email teachers or complete assignments.

36. Q: How will my child make up school assignments that they missed while participating in the program?

A: It is important that you contact your child's school as soon as you are given an admission date and request that your child's teachers gather assignments for several weeks of work. Your child will be able to work on those assignments over the weekends and in the evenings.

37. Q: Why does the program need to contact my child's school?

A: It is important that we plan your child's school re-entry with staff at the school. This will ensure an optimal school re-entry plan.

38. Q: Why do I need to sign HIPAA releases for school information?
A: *It is important that the team review your child's school records to determine if there are learning issues that require further attention. Additionally, the signed HIPAA allows the Education coordinator to collaborate with the school team to plan school re-entry.*
39. Q: Why can't my child have physical accommodations when they return to school?
A: *It is our goal that at the end of the program for your child to be fully functional. This includes being able to get around their entire environment, including school, without limitations due to pain.*
40. Q: What are academic accommodations?
A: *Academic accommodations are adjustments that are made in your child's class work and homework. Some typical accommodation include reducing assignments in size and extending assignment due dates.*
41. Q: How can I make sure my child receives them when they return to school?
A: *The Education Coordinator will contact the school and verbally request these accommodations. This conversation will be followed up with a letter which is sent to whoever the parent decides is the best advocate for their child.*
42. Q: Why can't my child remain on homebound instruction following their discharge from the program?
A: *It is vital that your child return to school on a fulltime basis. This is the goal of the program. A return to school on a fulltime basis allows your child to maintain all of the functional gains that have been achieved as the result of participation in the program. It also allows for him or her to reconnect with friends and participate in the social activities associated with school (clubs, student government, sports, cheerleading, drama, etc).*
43. Q: Will my child return to school full time as soon as the program is over?
A: *For most children, yes. Sometimes we gradually introduce the child to school by having them attend the program here on Monday, Wednesday and Friday of their last week and go to school on Tuesday and Thursday. This allows them to be reintroduced to school while still supported by our team. Some children will need to go to school but not necessarily go to all classes, that is, they will need to work on their make up work with their teachers and tutors in study hall. They need to be in the school building during school hours. This way they can connect to their friends, eat lunch in the cafeteria, maintain a normal sleep/wake cycle and avoid naps. They may or may not have to do gym class depending on individual factors but most should participate in gym and other vigorous activities including competitive sports.*

Music Therapy Questions:

44. Q: What is music therapy?
A: *Music Therapy is an established healthcare profession that uses music as a tool to address physical, emotional, cognitive, and social needs of individuals of all ages. Music therapists strive to increase the quality of life for all persons (i.e., wellness population, children and adults dealing with disabilities, injuries or illnesses). Music therapy interventions aim to promote wellness, manage stress, alleviate pain, facilitate expression, enhance self-esteem, increase socialization and promote physical rehabilitation.*
45. Q: What happens in music therapy?

A: Every child in the RND program is provided with Music Therapy services 2 times per week. The focus lies on facilitating methods of coping and promoting self-expression. Methods of coping include music-assisted relaxation techniques to promote relaxation and mind/body connection through deep breathing, music and imagery. Relaxation and deep breathing with music may also help with those having difficulty sleeping. Self-expression is facilitated via song-writing, music production, lyric discussion and music improvisation. This proves to be a safe and non-threatening way for the child to express and to explore his or her feelings and thoughts. The music therapist incorporates functional tasks such as playing of musical instruments to encourage improved extremity function when involved.