



I've Got This: Helping Our Children Help Themselves

| | Common Barriers to Adherence | Methods for Increasing Adherence | Age Appropriate Tasks |
|----------------------------|--|---|---|
| Young Children | Fear of needles | Provide choices | Help gather supplies; pick out band-aid |
| | Preference for activity; not want to sit still | Make medication taking fun - designate an activity as something that is only done during infusions | Help mix factor |
| | Lack of motivation to cooperate due to focus on the present and lack of understanding of future consequences | Motivators / Rewards - not a bribe, increases cooperation by creating a positive association; something child would not receive otherwise | Help look for veins; help tighten tourniquet |
| | Inconsistent parental behaviors | | Help parents push syringe |
| School Age Children | Desire to be "the same"; start to recognize they are different than their peers | Discuss how to include/inform peers. Find ways to have contact with other children who have a bleeding disorder | Start self-infusions in front of parent |
| | Time commitment and preferring to be involved in other activities | Be flexible and try to do infusions around other activities | Help record infusions in a log |
| | Remain focused on the present and lack understanding about doing something to prevent future consequences | Offer choices, make medication taking fun, provide rewards/motivators | Help remind parents to order more supplies; help put supplies away when delivered |



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| Adolescents | Social stigma, desire to fit in | Provide opportunities to interact with other adolescents who have a bleeding disorder | Self-infuse on a regular basis |
| | Busy schedule | Support flexibility with infusion schedules so they don't feel they're "missing out" on anything | Keep infusion log (which parents check regularly!) |
| | Forgetting | Develop behavioral methods to help them remember (cell phone reminders, charts, visual cues) | Recognize when supplies are low and place orders |
| | Parent not actively involved | Even when they're mastered self-infusion, parents need to stay actively involved. Even if only to be present, acknowledge | Start to make medical appointments |
| | Anger - may act out by not following medical regimen | Encourage them to be involved in discussions with medical providers to be certain they cognitively understand the risks associated with poor adherence | Advocate for themselves in the medical setting |