

# DIACEPH MONITORING INSTRUCTIONS

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## DiaCeph Method and Monitoring Overview

The following are your “user instructions” for the DiaCeph Monitoring Forms. These instructions, in conjunction with any verbal instructions I may give, will assist you in obtaining NPH and shunt performance data on your NPH (hydrocephalus) medical condition. These instructions and the monitoring forms are bound in this binder. The monitoring forms have been “color coded” to assist you in reading and filling in the forms.

DiaCeph monitoring should be done every day for 10-14 days, “6 times” or more per day, and per the times (or as near to) those identified on the monitoring form. The times are: awaking in am, at 9am, 12 noon, 3pm, 6pm, and 9pm or bedtime ((1) see form). To begin, write in your awaking time in **Awake\_\_\_ a.m.** Then, select your sleep quality by circling one of the selections (2) **Sleep Q: G (good), F (fair), or P (poor)**. At Bedtime, write in the time you go to bed next to **Bedtime @\_\_\_** and monitor as usual. Each form covers two (2) days.

You are to monitor six (6) complaint “markers” (No’s 3-8) that define your NPH status. I’ve added four (4) additional monitoring slots (No’s 10-13) at the bottom of each form for (No. 9) **Activity Monitoring Challenges**, or specific activity monitoring. You are to coordinate these along with your scheduled daily monitoring.

Your markers include: (3) **Walking**, (4) **Urinary (urgency)**, (5) **Vision**, (6) **Cognitive**, (7) **Energy**, and (8) **Hall Steps #Count**, and should be recorded at the times

set on your monitoring form, along with the four **(9) Activity Challenges** discussed in these instructions.

Four (4) of your markers can be recorded with a momentary observation and assigning of a “numerical score” between N and 3 to your complaint levels, and writing in that score in the designated column/space. **For scoring**, use N = your most favorable observation for the complaint, 1 = mild level of the complaint, 2 = moderate level of the complaint, and 3= severe level of the complaint. Then, write in your numerical observation for each of the four markers.

Your **Cognitive** marker **(6)** is to be scored as **N/5**, where **N**= the number of “words, TV stations, household items, etc.” you can recall out a total of 5 you try to memorize. If 5 items is not challenging enough, we can raise the number to 8 or 10. The **Hall Step Count (8)** is to be scored by walking in your hall way with your arms out-stretched toward the walls, and “counting” the “number of steps” you are able to take before taking a “mis-step.” Try also to be consistent in your walking speed.

The “**Activity Monitoring Challenge**” **(9)** at the bottom of each form is to be used to monitor a challenging physical or mental activity, a long afternoon rest, or a stressful event. You should note these also with near scheduled monitoring, by making “notes” in the spaces of **(1)** 9am, 12 noon, 3pm, and 6pm. Enter or circle number **1, 2, or 3** corresponding to your level of activity, where 1 = minimum, 2 = moderate, and 3 = heavy level of activity. The activities included are: a) **(10) Time on Feet: Level 1 2 3**, b) **(11) Lying Down: Level 1 2 3**, c) **(12) Physical Activity: Level 1 2 3**, and d) **(13) Mental Activity (or stress): Level 1 2 3**.

You can use the **(9) Activity Challenges** and “spaces” next to time of day to monitor the

**effects of mood, stress, medications, and other triggers on your NPH markers. Write in the activity of the suspected trigger in the space next to the time of day, and write in 1, 2 or 3 for its severity level. Then, write your “scores” in for your six markers as you normally would. Neuropsychological assessment can also help reveal subtle changes in cognition associated with hydrocephalus. Similarly, gait assessments, can help document subtle changes in gait associated with NPH shunting and valve settings.**

**With 10 – 14 days of monitoring, I can generate shunt performance data and curves on your NPH status. The more you monitor with this method, the more accurate the scoring and results become. This methodology follows that each patient shunted for hydrocephalus or NPH (or with any medical condition, for that matter) exhibits a specific set of identifiable “distribution curves” of their complaint markers, and that the markers can be used to track how physiologically well each is treated.**

**Your first period of monitoring, along with your ventricular size on CT, is your baseline. In your case, your present post surgical status is your baseline. In a best case scenario, we would have used DiaCeph monitoring prior to your initial surgery, to compare pre and post surgical markers. Monitoring can also be done in tandem with a single ICP tap. Should your Strata valve be adjusted, this monitoring can help detect slight changes in your status. Your vision, energy levels, and sleep quality markers are included so as to examine their impact on your gait and urinary complaints.**

**Once monitoring is concluded, I will use the data to generate curves of your markers, and in conjunction with my medical workup and review of your records, I will compile a detailed “report” of my findings, analysis, and recommendations that will help your physicians determine if you would benefit from further revision and/or shunt adjustments.**

## Getting Started with your Monitoring

To start your monitoring, place the DiaCeph binder and forms near your bedside at night so you can record your first data points when you awake in the a.m. To begin, write in your awaking time on the form in the space next to **Awake\_\_\_ a.m.** Then, select your sleep quality by circling either of **(2) Sleep Q: G (good), F (fair), or P (poor)**. Feel free to also write in any **additional thoughts or observations** on the forms, as long as the form remains legible. Next, find your complaint markers on the form.

## (No's 3-8) Scoring and Recording of Complaint Markers

These markers have been selected for in-home monitoring. Four (4) of these require only a momentary observation, and writing in a "score." The scoring system is N – 3, where N = your normal level for that complaint marker. 1 = mild level of complaint. 2 = moderate level of complaint. And 3 = severe level of complaint for that marker. The markers appear on the form in an order of succession. You are free to change the order, but any changes should be done consistently to minimize human error. The **(6) Cognitive** and **(8) Hall-Step Count #** markers will take five minutes or more for each, and perhaps are best done last.

### Score your markers as follows:

**(3) Walking** - using N – 3 Scoring Scale, from N = best, 3 = worst. This marker is a generalized quick assessment of your ability to walk at that moment in time. Write in the score between N and 3 that describes your walking status. You will be doing a more detailed "step count" in your hall way as part of **(8) Hall Steps #Count**.

**(4) Urinary** - using N – 3 Scoring Scale, from N = best, 3 = worst. This marker is used to describe and score your urinary urgency and frequency problems. As you shared that you

have an underlying prostate issue, you need to be attentive to how you score this marker. Your sleep status will also impact these. Look for specific “features” of your urinary complaints that pare your walking difficulties, and soon you will begin to report your Urinary marker with more confidence. Again, the scoring is applicable only to this moment in time.

**(5) Vision** - using N – 3 Scoring Scale, from N = best, 3 = worst. This marker can be scored rather easily by writing in the degree of ease or difficulty you have when looking around your home setting, as well as reading these user instructions and forms. Score this from N - 3.

**(6) Cognitive** - using N/5, where N = number of items you were able to recall, and 5 is the total number of items memorized. You can vary this marker between the TV station test and items around the house. If 5 items are not sufficiently challenging, let me know, and we can raise the number to 8 or 10 items.

**(7) Energy** - using N – 3 Scoring Scale, from N = best, 3 = worst. This marker is intended to get a quick assessment of how much energy you seem to have at that moment in time. You might determine this by how easily you can stand up, or reach for something around the house. Obviously, when your balance is better, you will also seem to have more energy. Try to discern a difference between balance and energy.

**(8) Hall Steps #Count** - count your number of steps before taking a mis-step. This marker, as we discussed, should be done in the long hall-way of your home. The goal is to see how many steps you can take before you lose your balance or take a mis-step. I would suggest that you extend your arms out so as to touch both walls, and see how well you are able to walk. Count your steps taken before you have a mis-step, and write that number in

the space provided on the form.

Now that you have gone thru **awaking am** monitoring, continue to do so at these approximate times: 9am, 12 noon, 3pm, 6pm, and Bedtime (see **(1)**). Write in your **Bedtime @\_\_\_** time for your last monitoring of the day.

Note: The above times are approximate. You have up to an hour on either side of the time slot before the data might become skewed. Next up, is monitoring of your daily and special **Activity Challenges (9)**.

### **(9) Activity Challenges and Interventions (Scoring 1 - 3)**

The **Activity Monitoring Challenges** at the bottom of each form are to be used to monitor your markers after you undergo a challenging physical or mental activity, a long afternoon rest, or stressful event. There are four activities to choose from for each 2-day period. If you record an activity not listed on the form, “**write in**” that activity in the open space next to the time of day, and **write in a 1, 2, or 3**, corresponding to: 1 = minimum, 2 = moderate, or 3 = heavy level of activity or trigger.

The listed activities include: a) **(10) Time on Feet: Level 1 2 3**,

b) **(11) Lying Down: Level 1 2 3**, c) **(12) Physical Activity: Level 1 2 3**, and d) **(13) Mental**

**Activity (or stress): Level 1 2 3**. Familiarize yourself with your activities and triggers that might exacerbate your NPH related complaints, and incorporate them into your daily monitoring routine. You can use this methodology to liberally monitor nearly any activity that seems to exacerbate your NPH complaints. This can include physical exertion, mental challenges, stress, mood, or even medications.

The above section can also be used to evaluate “interventions,” such as wearing an abdominal/spine wrap to slow CSF flow in cases of suspected overdrainage. At this time, I don’t have any interventions to include in monitoring.

### **Tips and Precautions in Starting/Finishing your Monitoring**

This DiaCeph monitoring system has been designed to monitor 95% or more of what you will encounter in your everyday life that might impact your NPH status. My first word of caution is for you to fill in your data “carefully” to minimize any writing or reporting errors. I have pre-dated your forms and inserted them into the binder in order of their date, to avoid any confusion over days and dates. It is best not to remove the forms from the binder unless absolutely necessary. I have included additional blank forms should any become illegible. Please use care not to “injure” yourself while doing any of this monitoring. Be methodical and consistent, and your scoring will reflect an accurate representation of your status. If you have any questions, do not hesitate to contact me.

I have Fedex-ed these instructions and forms to you so that you can monitor.

### **Caring for the DiaCeph Binder and Completed Forms**

Please take care of the completed forms to assure their integrity. For your convenience, I have assembled them into a binder. Unless absolutely necessary, please do not remove any of the forms from the binder.

I will generate a report from your monitoring, along with my work-up of you. Should your physicians later change your shunt setting, you may want to again monitor your status. We can discuss this when and should this occur.

**Please contact me if you have any questions regarding the monitoring.**

**Very Truly,**

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