

A DAY IN THE LIFE CARING FOR JJ

DOB: June 9, 2006

Below is a real-life example, contributed by a CPN parent, of a family's day-in-the-life schedule.

MEDICAL PROBLEMS

- Myoclonic epilepsy 8/5/2008
- Developmental delay, non-verbal, & non ambulatory
- Regression
- Heart murmur 6/2007 Echo 4/2009 showing nothing abnormal
- Anemia 5/2008
- Aspiration on liquids 7/2010 (nectar thickened)
- Thicken more nectar 3 not 4oz 7/2012
- Tremor (unknown date but before age 1)
- Urinary cathing 12 French as needed - normally 2x day
- G-tube 11/13/2012 Mic-Key button - 16 French 3.5cm 3/115/2013
- Rare genetic disease identified 2013
- Mildly prolonged QT intervals 8/2020

FOOD RECIPE AND FEEDING TIMES

- 9a,10a, 11:15a, 12:30p, 2p, 3:30p, 5p, & 6:30p
- 24oz Compleat Pediatric + 7.5tbs baby cereal
- 2-4oz #2 baby food total + 2 jar baby food meat
- Applesauce mix: 6oz applesauce + 10oz water
- Feed times each 100ml bolus + 60ml applesauce mix
- 30ml water to follow by gravity

DAILY ACTIVITIES

- Specialist appointments include:
 - epilepsy
 - ortho
 - physiatry
 - complex care
 - urology
 - endocrinology,
 - pulmonology
 - cardiology
 - aerodigestive
 - ORL metabolic
 - palliative care
- PT 3x/week
- OT 3x/week
- School 4x/week
- Speech therapy 2x/week

ALLERGIES

- No known allergies but avoid:
 - Augmentin causes diarrhea
 - Zonagran
 - Zarontin causes vomiting
 - Gabapentin

MEDICATIONS

- Meds given at 8:30a, 1:30p, 8p & as needed for symptom management or seizure activity
- Calcium carb 1.250mg/5ml: 2ml at bed
- Centrum Vitamin: 1/2 tab am
- Culturelle Kids: 1 packet AM
- Glycopyrrolate 1mg per tab: 2 tab A.M. 1 tab 1:30 & 2 tab Bed
- Cyproheptadine 2MG/5ML: 10 ML @ Bed
- Valproic Acid 250 MG/5 ML: 5 ML A.M. & 1:30 P.M. 7.5 ML @ Bed
- Diazepam 5MG/5ML: 7.5 ML A.M. 6 ML 1:30 & 17.5 ML @ Bed
- keppra 100MG/1ML Brand Only: 22 ML am and 21ML 1:30 and @ Bed
- Lamical 25 mg tabs Brand Only: 5 Tabs A.M. 4 tabs 1:30, 3 tabs @Bed
- Levocarnitine 100MG/ML: 3.3 ML 3 Times a day
- MiraLAX 17.5 g: 1 cap @ Bed
- Motegrity 2MG: 1 pill in morning
- Nexium 20MG packet.: 1 packet in morning
- Onfi 2.5 MG/1ML Brand Only: 5 ML in am & 4.5 ML at 1:30
- Vitamin C 500mg chewable: 1-3 pills in morning
- Zyrtec: 10 ML once a day
- Nayzilam 5mg per spray: 1 spray Per nostril (10mg) for seizure more than 5 minutes
- Lorazepam 2MG/ML: 0.5 ML @ 10, 15, 20, 25 minute seizure mark
- Diastat 12.5 mg rectal: Give one dose at the 30 minute mark

Note: Courageous Parents Network does not recommend or endorse any treatments, including interventions, protocols and/or medications. Please consult your medical team.

