Follow-up Forms-Adult Data Collection Tools © A.S.P.E.N.

Follow-up Demographics

● Follow-up Date (mm/dd/year): __________________________

Patient Number (As designated by study)________________________

● Attending Physician’s Name______________________________

● Discharging Institution Name___________________________

● PN Home Infusion Care Provider Name________________________

● Patient Birth Date (mm/dd/yr) __________________________

● Gender: Male___ Female____

● Date began Home PN (mm/dd/year)________________________

Who does patient live with? (please select)

   Alone____
   Parent____
   Spouse____
   Significant Other____
   Child____
   Hired professional assistance____
   Other____

● Insurance Coverage (check all that apply)
   Private Insurance___
   Medicare___
   Medicaid___
   Personal Payment___
   Medicare Supplement___
   Other (Specify) ______________________________

Current Nutritional Status

● Height _____ cm   Length for Infants or bedbound children ________cm
If extrapolated, please explain and indicate method used ____________________

- Usual Weight _____ kg (prior to illness)
- Current Weight _____ kg

Labs at Followup

Date Labs collected: (mm/dd/yr)_______________

- Serum Albumin_____ g/dL
- Platelet Count _____/µL (per microliter)
- Direct Bilirubin_____ mg/dL
- AST_______U/L
- ALT______U/L
- INR______
- BUN_____mg/dl
- Creatinine_____mg/dl

Any New Diagnoses (check all that apply)

- AIDS
- Esophageal Atresia
- Intestinal Atresia
- Gastrochisis
- Crohn's Disease
- Cystic Fibrosis
- Gastrointestinal Cancer
- Gastromotility/Pseudo-obstruction disorder
- Gynecological tumor
- Hirschsprung's Disease

- Hyperemesis Gravidarum
- Gastrointestinal Bypass for Obesity
- Mesenteric Ischemia
- Mitochondrial Disorder
- Necrotizing Enterocolitis
- Neurological Swallowing Disorder
- Non-Crohns Inflammatory Bowel Disease
- Pancreatitis/Pancreatic Insufficiency
- Radiation Enteritis

- Short Bowel Syndrome
- Small bowel stoma _____ Yes ______ No
- Colonic Stoma _____ Yes ______ No
- Large bowel in continuity with small bowel
  - Yes 
  - No
- Ileo-cecal valve present _____ Yes ______ No
- Length of remaining small bowel in continuity ______ cm
- Length of remaining large bowel in continuity ______ cm
- Bowel measurement technique (before any lengthening procedure):
  - At time of surgery
  - Radiographically
  - Estimated
- History of bowel lengthening surgical procedure Yes____ No____
  - If yes, operative procedure used:
Length after lengthening surgery:

Other Diagnosis Please specify:

Ongoing Reason for Parenteral Nutrition (check all that apply)

- Active Inflammatory Bowel Disease
- Bowel dysmotility
- Chemotherapy Associated GI Dysfunction
- Congenital Bowel Defect (Intestinal Atresia)
- Gastrointestinal Fistula
- Gastrointestinal Obstruction
- Gastrochisis Associated Dysmotility
- Intractable Diarrhea
- Intractable Vomiting
- Mesenteric Ischemia
- Necrotizing Enterocolitis
- Neurological Swallowing Disorder
- Non-Short Bowel Diarrhea/Malabsorption
- Pancreatitis
- Radiation Enteritis
- Short Bowel Syndrome
- Other Please specify:

Goals of PN therapy (check all that apply):

- Weight gain
- Weight maintenance
- Weight loss (for the Gastric Bypass patient with a fistula for instance)
- Future surgery and re-establishment of GI anatomy
- Indefinite (permanent) HPN
- Resolution of GI issue and stopping HPN

Current PN Formula

PN Infusion (check each day that PN infused)

- Sunday
- Monday
- Tuesday
- Wednesday
- Thursday
- Friday
- Saturday

Total volume in ml _______ per day or _______ mL/kg/day
Total Dextrose in g [___] per day or [___] g/kg/day or Dextrose infusion rate in mg/kg/min: [___]

Total Protein as Amino Acids in g [___] per day or [___] g/kg/day

Cycled over [___] hrs

Daily

- Sunday
- Monday
- Tuesday
- Wednesday
- Thursday
- Friday
- Saturday

**IV Fat Emulsion** (check each day that fat emulsion infused)

- Sunday
- Monday
- Tuesday
- Wednesday
- Thursday
- Friday
- Saturday

IV fat emulsion [___] g per day or [___] g/kg/day

- Soybean/Safflower
- Soybean only
- Emulsion containing Omega-3 fatty acids
- Other: [___]

**Food/Diet** (Check all that apply)

- NPO
- On concurrent enteral nutrition
  - What % calories come from enteral: [___]
  - What type of enteral formula is the patient on? Name of product: [___]
- Liquids or oral rehydration only
- Food and/or beverages for comfort only
- Restricted/therapeutic diet
- Ad lib

If on oral nutrition, what % calories come from oral: [___]

**Date PN Discontinued** (mm/dd/yr) _________________
● Reason PN Discontinued (check all that apply)

___ Patient transitioned to oral diet___
___ Patient transitioned to enteral nutrition___
___ Patient had small bowel transplant _____
___ Patient had surgery to restore intestinal continuity___
___ Patient converted to IV fluids_____ 
___ Patient completed PN therapy course____
___ Patient placed on hospice care____
___ Patient Expired____
___ Patient hospitalized for some other reason _____
    Please explain________
___ Other ____ Please explain______________________________
______________________________________________________________________________

● Type of central venous catheter

☐ PICC  
☐ Port  
☐ Tunneled catheter
☐ Other

Lumen: Single Lumen _____ Double Lumen______ Triple Lumen____

Date of Insertion:(mm/dd/yr)____________________________

How often is dressing changed?(please select)  Daily____, QOD____, 3 x week, Weekly

Who is changing dressings? (please select)  Patient____ Caregiver_____ Both____ Visiting Nurse____

● Check Medications on Discharge (Check all that apply)

☐ Anti-infective Agents  
☐ Antineoplastic Agents  
☐ Autonomic Drugs
☐ Cardiovascular Drugs
☐ Central Nervous System Agents
☐ Electrolytic and Water Balance (other than PN)

☐ Gastrointestinal Drugs (check all that apply)
☐ Antacids and Adsorbents
☐ Antidiarrhea Agents
☐ Antiflatulents
☐ Cathartics and Laxatives
☐ Cholelitholytic Agents
☐ Digestants
☐ Emetics
☐ Antiemetics
☐ Lipotropic Agents
☐ Antiulcer Agents and Acid Suppressants
☐ Prokinetic Agents

☐ Hormones and Synthetic Substitutes
☐ Pain Medications
☐ Vitamins (Other than PN)____ Ethanol lock
### Morbidity

#### Re-hospitalization Information

- **Patient admitted directly to:** ICU________ general med-surg unit________

- **Reason for this rehospitalization** (CHECK ALL THAT APPLY)

  - [ ] Surgery
  - [ ] Bleeding
  - [ ] Sepsis not related to catheter
  - [ ] New Medication
  - [ ] Chemotherapy regimen
  - [ ] Catheter related
    - [ ] Catheter related to bloodstream infection
      - [ ] Yes___ No____
      - [ ] Was patient given antibiotics for catheter related bloodstream infection?
        - [ ] Yes___ No____
      - [ ] Type of organism:
      - [ ] Did patient have skin/tunnel/pocket infection?  [ ] Yes  [ ] No
  - [ ] Thrombosis/Occlusion
    - [ ] Was catheter removed during this hospitalization? Yes____ No____
    - [ ] Anticoagulation regimen? [ ] Yes  [ ] No  If yes, describe:
  - [ ] Other treatment for occlusion? [ ] Yes  [ ] No  If yes, describe:
    - [ ] Incorrect position (Outgrown)
    - [ ] Damage (leak, crack)
    - [ ] Other:
  - [ ] Fluid and electrolyte imbalance
  - [ ] Psychological/substance abuse
  - [ ] Myocardial infarction
  - [ ] Congestive heart failure
Cerebral vascular accident
Pulmonary embolus
Trauma
Obstruction
Other:

Unknown (This category is for patients who were re-hospitalized but for unknown reasons—for example, patient may have been re-hospitalized elsewhere)

Describe:

If catheter removed during this hospitalization, was another central venous access placed for PN?

Yes____ No____

Type of central venous catheter:

- PICC
- Port
- Hickman/Broviac
- Other

Lumen: Single___ Double____ Triple_____

Date of Insertion (mm/dd/yr):

Place of Insertion:

- Surgical OR____
- Radiological Suite____
- Bedside____

How often is dressing changed? (please select)

- Daily
- Every Other Day
- 3 x week
- Weekly

Who is changing dressings? (please select)

- Patient
- Caregiver
- Both
- Visiting Nurse

Metabolic Issues

(check all that apply)

- None
- Fluids and electrolytes
- Hyperglycemia
- Hypoglycemia
Organ failure (requiring or not requiring transplantation) (check all that apply)
- Liver failure
- Renal (requiring dialysis or not)
- Heart
- Pulmonary (requiring ventilatory support or not)
- Other:

Metabolic Bone Disease: Yes____ No____
First diagnosed by
- DEXA
- Bone Fracture

Mortality
- Date of Death (mm/dd/yr)_____________________
- Date Unknown? Approximate Date: (mm/yr)_____________________
(please select)
- Family/caregiver
- Clinician/healthcare professional
- Public Records
- Other:

Causes of Death HPN Related
- Cause of Death HPN Related Yes_____ No_____
(check all that apply)
- Vascular access (check below all that apply)
  - sepsis
  - thrombosis
  - other:
- Metabolic (check below all that apply)
  - fluids and electrolytes
  - hyperglycemia
  - hypoglycemia
  - other:
- Organ Failure (check below all that apply)
  - liver
  - renal
Other Causes of Death

Death Related to Underlying Diagnosis
☐ post operative bleeding, explain:
☐ bleeding
☐ sepsis
☐ other:

Death Related to Reason for HPN
☐ post-operative
☐ bleeding
☐ sepsis
☐ other:

Myocardial Infarction
☐ Congestive Heart Failure
☐ Cerebral Vascular Accident
☐ Pulmonary Embolus
☐ Other Cancer
☐ New Trauma (i.e., accident, fall, gsw, etc.)
☐ Other:
☐ Unknown
Describe circumstances:

Current Psychosocial

Neuropsychological problems
☐ Depression_____ (If yes, complete depression/anxiety))
☐ Dementia____
☐ Personality disorder _____
☐ No psychological problems____
☐ Other____

Depression/Anxiety (check all that apply)
☐ Pre-existing (pre-HPN) diagnosis of major depression (APA, DSM-IV, 1994)
☐ Pre-existing (pre-HPN) diagnosis of anxiety disorder
☐ New diagnosis of depression requiring treatment (behavioral or pharmacological)
☐ New diagnosis of anxiety requiring treatment (behavioral or pharmacological)
☐ New treatment for situational depression

'Quality of Life:

Has Quality of Life Instrument Been Administered? Yes ___ No ___

☐ Quality of Life Instrument (QOLI) Date administered: ______ Score: ______
☐ Quality of Life Index (QLI) Date administered: ______

Overall Score: ______ (0-30)
Health and functioning subscale: ______ (0-30)
Social and economic subscale: ______ (0-30)
Psychological/spiritual subscale: ______ (0-30)
Family subscale: ______ (0-30)

☐ Short Form - 12 (SF 12) Date administered: ______
Physical Functioning (PF): ______ (0-100)
Role-Physical (RP): ______ (0-100)
Bodily Pain (BP): ______ (0-100)
General Health (G): ______ (0-100)
Vitality (VT): ______ (0-100)
Social Functioning (SF): ______ (0-100)
Role-Emotional (RE): ______ (0-100)
Mental Health (MH): ______ (0-100)
Component Summary Physical Health: ______ (0-100)
Component Summary Mental Health: ______ (0-100)

☐ Short Form - 36 (SF 36) Date administered: ______
Physical Functioning (PF): ______ (0-100)
Role-Physical (RP): ______ (0-100)
Bodily Pain (BP): ______ (0-100)
General Health (G): ______ (0-100)
Vitality (VT): ______ (0-100)
Social Functioning (SF): ______ (0-100)
Role-Emotional (RE): ______ (0-100)
Mental Health (MH): ______ (0-100)
Component Summary Physical Health: ______ (0-100)
Component Summary Mental Health: [0-100]

HPN QOL (Baxter) Date administered: [ ] Score: [ ]

Inflammatory Bowel Disease Questionnaire (IBDQ) Date administered: [ ] Score: [32-224]

Other: [ ] Date administered: [ ] Score: [ ]

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**Current Functional Status**

Mobility (please select)
- [ ] Independent
- [ ] Requires minimal assistance (25% assistance from caregiver)
- [ ] Requires moderate assistance (50% assistance from caregiver)
- [ ] Requires maximum assistance (75% assistance from caregiver)
- [ ] Completely dependent on caregiver for mobility

Activities of Daily Living (ADL) (please select)
- [ ] Independent
- [ ] Needs partial assistance
- [ ] Totally dependent
- [ ] Requires skilled home nursing care
- [ ] Pediatrics: Age appropriate dependence

Care of Catheter and HPN related procedures (please select)
- [ ] Independent
- [ ] Needs partial assistance
- [ ] Totally dependent
- [ ] Requires skilled home nursing care

Able to return to work or school  Yes_____ No_____  

Employment Status (please select)
- [ ] Working full time
- [ ] Working part time
- [ ] Not working
- [ ] Student

If not currently working, please check all that apply:
- [ ] Retired
- [ ] Medical disability
- [ ] Health related leave of absence
- [ ] Not working because of health
- [ ] Not working because of insurance coverage

Who is the primary caregiver at home? (please select)
- [ ] Self
- [ ] Parent
- [ ] Spouse
- [ ] Significant Other
- [ ] Child
Who is primarily responsible for administration of PN at home?

- Patient
- Parent
- Spouse
- Significant Other
- Child
- Hired Professional Assistance
- Other: __________________________

Community Resources/Support Group

Confirmed that patient has information on HPN specific community resources and/or Oley Foundation: (please select)

- Yes
- No
- N/A

Participates in local support group for HPN and/or Oley Foundation (please select)

- Yes
- No

Pediatric Element: Participates in (check all that apply)

- Infant/toddler services
- Early childhood intervention
- WIC
- OT
- PT