

# DEAN

## ESSENTIAL LIFESTYLE PLAN

12/1/99 - Held at Dean's Home

**Note:** Dean is a handsome young man who has been described as a survivor. He has complex medical needs and his plan was developed so that everything that his caregiver knew about helping him stay alive and happy would be available to anyone else who would support him. Dean does tell you important things about his support but not with words. For example, Dean eats for fun (most nutrition goes in through a g-tube) and loves pudding. If he doesn't eat his pudding at one meal it means he doesn't feel well if he doesn't eat his pudding for 2 meals in a row you should call his doctor.

*Persons in attendance:* Dean.  
Dicky, Dean's Father  
Kathy, Provider/Co-facilitator  
Carey, Sr. SW/CM  
Diane, RN, Nurse Consultant  
Amy, Easter Seals  
Emma, Friend-Personal Care Assistant  
Joy, Sr. SW/CM/Co-facilitator

*With input on Medical issues:*

Dr.  
Dr.  
Dr.

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## What People Like and Admire About Dean

- VERY good looking/handsome
- a sharp dresser
- got Gorgeous hair - can't keep the women out of it
- a survivor
- a real charmer
- wonderful son/brother
- lovable
- has helped others to understand "Life" all over the country
- makes other men jealous
- great date
- great smile
- wonderful company
- educates people to listen in a new way

## What Dean Must Have In His Life

- Eating - especially pudding at least twice a day any flavor, and people to listen to what he's telling you while he's eating.
- Keep him warm - he hates being cold.
- People to help him with his personal care, the way he wants it done.
- going out and doing things in good weather at least a couple of times a week
- *People must listen to what he says, especially if he:*
  - \* *won't eat his pudding*
  - \* *bites his hand*
  - \**fusses or cries*
  - \**IF HE DOES THESE, THEN SOMETHING IS WRONG!!*
- Go to the Easter Seals CIL Program.
- Everyone who helps Dean in any way;
  - Must explain what is going to happen in a CALM voice.
  - Never be helped in a rough manner.
  - Help him with his personal care the way he wants it.
- Live with Kathy where he feels safe and loved and keep close ties with his family.

## Things Dean Likes:

### Things That Dean Really Likes:

- GOING, GOING, GOING OUT and riding in the car/van seat for hours on end (in a seat with a high back to it). (I.E.: food stores; sporting events; award ceremonies; friend's houses; 4<sup>th</sup> of July Parade; Pumpkin Chunkin; Washington, DC; out to eat; vacations - over night)
- Hugged and kissed by people he is close with and knows well. For now this includes: his sister Lori, his mother, father and Grandmother , Amy Maker as well as Emma, Kathy and Amy .
- Having his chest and back rubbed.
- Music of any kind. (Really likes classical)
- Going to bars/especially when there is live music and women.
- Warm weather - he doesn't like going out in the cold or extremely hot weather.
- Going out to eat:
  - McDonald's - fish sandwich with lots of tartar sauce; chocolate milkshakes
  - Rehoboth Country Grill - sweet potato soufflé; string bean casserole; mashed potatoes; turkey with dressing; chicken and dumplings; crab cakes
  - Rusty Rudder - cottage cheese with applesauce; mousse; cream chipped beef; crab cakes; pancakes
  - Grotto's - tuna fish; spaghetti or manicotti
  - Lamppost, Lighthouse & Angler's Irish Eyes, Crab Barn - crabcakes
  - Arners - turkey, fish, mashed potatoes, cottage cheese with apple butter
  - Fisherman's Inn (Kent Island) - crab cakes; salmon cakes
- Things that he likes to eat for breakfast:
  - scrapple/eggs/cheese
  - creamed chipped beef
  - pancakes (with lots of butter and syrup)
  - cream of wheat (with real butter, 2 scoops of sugar & cream for each pkg.)
  - maple/brown sugar oatmeal (with cream)
  - apple/spice oatmeal (with cream)
- Things that he likes to eat for lunch:
  - tuna fish (with bread broken up in it)
  - egg salad (with bread broken up in it)
    - Lunch buckets – chili (no beans), mac & cheese, beef stew, chicken & dumplings, beef ravioli, pizza wedges, cheese twists, hot dogs & baked beans
  - applesauce cinnamon with berries, bananas

### **Things that Dean really likes: continued**

- Things that he likes to eat for dinner:
  - Fridays (tuna fish at home or crab cakes if we go out)
  - sweet potatoes or mashed potatoes
  - spinach (with butter, salt, pepper)
  - chili with mashed potatoes
  - turkey and dressing
  - beans and franks
  - spaghetti (not much garlic)
  - squash
  - broccoli and cheese
  - leseur peas (with butter, salt and pepper)
  - meatloaf
  - fish and macaroni & cheese
  - Turkey & Chicken pot pies

### **What he really doesn't like:**

- being cold
- wind in his face
- rain
- any kind of rough movement
- anything covering his face

## IN ORDER TO SUPPORT:

### Communicating with Dean

It's important for you to know that Dean doesn't/can't respond with smiles or eye contact to things he likes or when his name is called. No one **"KNOWS"** what he does or doesn't understand - so - we just go ahead and talk with him as you would any other 22 year old guy, just don't expect him to give you a response. Because of this we have to be very careful to listen to what we know are things he does tell us by his communication and the physical things we need to watch out for like his facial expressions.

**NOTE:** The following will help you better understand Dean with pictures of him facial expressions and communications tables for both Dean's communication to us and ours to him.

HAPPY / CONTENT

TICKED OFF

**Dean's Communication to Us.**

<b><u>When This is Happening</u></b>	<b><u>And Dean Does....</u></b>	<b><u>We Think It Means</u></b>	<b><u>Then We Should</u></b>
* <b>He is eating</b>	Dean won't eat his pudding	He may not be feeling well	Take his temperature (if over 100°, get appt. w/Dr. Choy)
	Dean won't eat his pudding for the 2 <sup>nd</sup> meal in a row	Something is really wrong	Call Dr. Choy as soon as his office opens
	Dean spits his food out	He doesn't want anymore of the food you are giving him	Stop feeding him that (Tip: Rotate what he is eating).
	Dean opens his mouth	He is ready for another spoonful	Give him one
	Dean won't open his mouth or turn his head	He doesn't want it	Stop trying -he's done
	Holds food in his mouth (barely opens his mouth)		Stop trying -he's done
* <b>In his Wheelchair</b>	Dean starts throwing his arms or fussing	He may be uncomfortable. (There are times when he can't control his arms and it doesn't mean anything).	1 <sup>st</sup> - Try to reposition him. If that doesn't work, then take him out of his chair.
* <b>Anytime</b>	Dean violently throws his arms, grits his teeth, and won't sleep for over 36 hours	There may be a medical problem	Watch him closely and call Dr. Naidu (if it continues for more than 36 hours)
	Dean bites his hand	He is in a lot of pain	Pay attention to what is happening and how he was positioned right before he started biting his hand
	Dean sleeps the majority of the day for 3 days	There may be a medical problem	Watch him and call Dr. Naidu if still occurring after 3 days
	Dean is quietly sitting (see picture)	He is content and likes what he is doing	Don't worry, be happy

**Dean's Communication to Us: continued**

<b><u>When This is Happening</u></b>	<b><u>And Dean Does....</u></b>	<b><u>We Think It Means</u></b>	<b><u>Then We Should</u></b>
* <b>Anytime</b>	Dean smiles or laughs out loud	He is VERY HAPPY with whatever is going on	Be Very Happy! This past year it's becoming a monthly/weekly thing. YEA!!!
	Dean grimaces (see picture)	He doesn't want to be touched or "messed with"	Leave him alone, if that is possible. (Note: He'll do it whenever you brush his teeth and wash his face & sometimes when you take off his shirt).
* <b>In Bed</b>	Dean keeps turning his head to the left	He wants to be put over on his left side	Tell him what you are doing then encourage him to start trying to help by lifting his right arm.
* <b>At Night (after 9 PM)</b>	Dean rubs his eyes	He wants to go to bed	Help him to bed (or tip his chair back if you are not able to put him bed at that point) and let him know you will get him in bed as soon as you can.
* <b>In the Bath Tub</b>	Dean moans/fusses	The water is probably too cold (He likes it really hot - 100°). In the summer, it does not need to be as hot.	Run more hot water in the tub
* <b>Wearing his Glasses</b>	Dean pushes his glasses	He wants them off or his eyes may be itching	Take the glasses off. After he's done itching, you can put them back on him.
* <b>Brushing his Teeth</b>	Dean begins crying and getting frantic	He thinks he is choking	Wait until he calms down. (See Personal Care section on brushing teeth).

**Our Communication to Dean**

<b>What we want Dean To know or Do</b>	<b>What we do</b>	<b>How Dean let's you know he understands</b>
Weekends coming	He eats Tuna Fish for dinner	We're not sure he does understand / but he's use to this happening every Friday
Anytime you do anything to help Dean	Tell him what your doing	Doesn't give you the ticked off look
Helping him eat	Touch the spoon to his bottom lip	He'll open his mouth
Helping him shave	Let him hear the electric razor until he stops making a face.	He has content look on his face / ready for you to shave him
Toothbrushing	Touch the wet toothbrush to his lips	He'll open his mouth a little bit so you can start

**Regarding Dean's General Support Needs - Things everyone needs to know to support Dean.**

Dean lives with Kathy . He has lived with her family since just before his 8th birthday.  
**Anytime you have any concerns, especially regarding Dean's health or his wheelchair, call Kathy.**

Kathy	Home Phone # 945-
Rt., Box	Work Phone # 934-
Georgetown, DE 19947	Car Phone # 381-
	Car Phone# 745- (work)
	Beeper # 822-

Dean's DMR Social Worker/Case Manager is Joy . His DMR Nurse Consultant is Diane , RN.

Address: Rd , Box Georgetown, DE 19947

Joy's Phone #: 934-

Diane's Phone #: 934-

### **Family/ Legal Guardians:**

Dean's parents, Dicky and Brenda , are Dean's legal guardians of person and property. In the event they cannot be reached, Kathy has durable power of attorney. His parents stay in close contact with Kathy to keep on top of how Dean is doing and are a big part of his life. He likes seeing them along with his sisters and grandmother whenever it can be arranged.

### **Eye glasses:**

- He is legally blind (cortically). No one is really sure what he actually sees.
- Dean wears glasses but, he does not like to wear them all the time. He will push them off when he wants them off or if his eyes itch. Watch out as sometimes they hang across his face, near his eyes. Because of this you should always be around when he has them on.
- His eye glass case is always kept in the side zipper pocket of his pouch case on the back of his wheelchair.
- He should definitely wear his glasses when outside in the sunshine. They turn dark and have UV protection.

### **Sunscreen:**

- Sunscreen 30+ is always kept in the side zipper pocket of his pouch bag on the back of his wheelchair.
- Make sure you put it on him if he's out in direct sunlight over 15 minutes.
- Dean burns easily due to the medicine he takes.
- Don't forget to also put on his eyeglasses.

### **Seizures:**

- normally has 7-9 a month, lasting 15-30 seconds (rarely up to 1-2 min.).
  - \*Signs - both arms raise up and sometimes shake, both legs stiffen, head goes forward, eyes open wide, sometimes eyes flutter, sometimes he makes a snorting sound.
  - \*You should - not do anything other than making sure his arms or legs don't hit anything. If in bed he should be turned on his side with pillows behind for support.
  - \*Afterward - his eyes stay to the side and he breaths at a faster rate.
- Make sure you tell Kathy how long each seizure lasts and if it's different than his normal seizure as she needs to record this data.

You also may see some seizure type activities where his head and eyes are stuck to the left. Some time his head also twitches and some times it doesn't. If you turn his head it will go right back to the left. Let Kathy know about this if you see it and about how long it lasts. Some times it lasts 2-3 hours.

- You MUST let Kathy or Diane , RN know if his eyes roll back in his head

**Continued:**

- This past year the Tegretol was discontinued.
  - His Neurontin and Phenobarb were increased to as high as they can go.
  - Lamictal was started 11/15/99 and will be to a therapeutic dose the beginning of January 2000.
  - Dr. Trescher has prescribed Lorazepam 1 mg / Ativan only to be given if:
    - Dean has more than 3 seizures in 1 hr.
    - Dean has more than 5 seizures in 24 hr
    - After giving him the pill (by mouth) call Kathy (822-0890) right away & if for any reason she can't be reached, call Diane .

- **Plan for this year**

After the Lamictal is at therapeutic range then Dr. Trescher plans to decrease one of the other medications so it's going to be awhile (months) until we get stabilized.

We're leaving space below for additional updates.

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## G-Tube: Info Everyone Should Know

- The only people who can tube feed Dean are nurses, LPN's, or people who have been fully trained by a nurse who knows him. His parents must give written permission unless they are an RN.
- Dean has a g-tube (MIC - Button) in his stomach for water and fluids only. He eats 3 meals a day. Usually it's flush with his skin – if you notice that it's sticking up make sure you let Kathy know as the balloon may have broken, you should also be very careful that nothing pulls at the button as the balloon inside may have broken and it will come out easily.
- He should never be left alone flat on his back, especially after eating.
- Dean is always tube fed water after his meals. If Dean drools, coughs, and moans he is probably having trouble with his bowels being backed up. It's most likely to happen in the evening. Let Kathy know if you notice this.
- He must have at least 2000cc of fluids (water or juices) daily through his g-tube. (**Note:** It is very important for Dean to get at least this amount of fluid per day or his bowel routine will be thrown off).
- Deans gets all tube feeding while sitting in his wheelchair. Tube feedings are not done in bed as he moves around too much.
- He always carries a spare g-tube in his backpack. A balloon on the end of the tube holds it in place. If the balloon breaks/springs a leak, the button will stick out a lot so let Kathy know. If for any reason it comes out, it's extremely important to contact Kathy or Diane , RN **ASAP**. Cover with 2x2/4x4-gauze pad. We only have a time period of 30-45 minutes that it can be put in. After that, Dean would have to go to a doctor or the emergency room.
- You must always be careful that nothing or no one is around him who may pull on the tubing.

### **Helping Dean eat:**

- He takes his medications – whole tabs or capsules 1 at a time in his food.
- BE PATIENT - don't try to rush him.
- Remember Propulsid always 15/30 minutes before meals. The rest of his meds at the end in his pudding.
- First, his wheelchair should be tipped all the way forward so he's sitting straight up. Also, make sure his buttocks is in the middle of his seat and all the way back in his seat.
- His hands should be in his lap. He may need you to remind and help him. Guide them back in his lap if his arms start flailing around, he tends to choke and it's very hard to feed him.
- ALL FOOD MUST BE MASHED. He doesn't chew his food, therefore, it must be a consistency that sticks together (i.e.: no dried rice).
- He can eat with any kind of teaspoon.
- He does better if you are sitting down with him.
- Never feed him if his head is back.
- Put the spoon full of food up to his mouth. He will open his mouth (usually not real wide). Put the spoon in his mouth. He will close his mouth and lips and you pull the spoon straight out.
- He does better if after several spoonfuls of one thing, you change to something else.
- Watch out that foods are not too hot.
- You know he really likes something when he opens his mouth wider, eats faster and doesn't let any fall out of his mouth.
- If he holds food in his mouth or coughs or laughs, he doesn't want to eat so STOP feeding him!!!

### **Drinking:**

- We think Dean doesn't like to drink. If he drinks 4oz. it's great. No need to push it because he gets it through his g-tube.
- He can drink out of any kind of cup.
- At home, he uses a 5oz. plastic cup which works well
- Always make sure his head is down - never give him a drink with his head back and mouth open.
- Put the cup up to his lips. When he puts his top lip down, tip the cup so fluid covers his top lip.
- He will turn his head when he's had enough.
- Favorite thing to drink have been Nestle's chocolate milk, V-8 juice, apricot nectar, milkshakes, tea (sweetened). Try things out. Usually, he doesn't like carbonated drinks, but lately he'll try them.
- If he coughs or spits it out, stop.

### **Keep Warm & Not Cold**

In cold weather – even if his inside feel his legs to make sure they aren't cold – if they are put on long underwear or a pair of sweat pants and heavy socks.

### **Safety in his wheelchair:**

- Safety in his wheelchair - when you put Dean in his wheelchair, his buttocks must be all the way back and in the middle of the seat. When you're sure his buttocks is back, put on his seatbelt and pull the plastic loops on both sides tight.
- Whenever he goes on the bus, he must have on his chest straps/vest.
- If he doesn't have his chest straps on and he doesn't have his buttocks in the middle of the wheelchair, he can get his head caught outside the headrest (left side) -SO- always make sure he's seated properly. It's especially a problem when he's real active.

### **Easter Seals:**

- Dean goes to Easter Seals CIL program in Millsboro. Amy Maker is his Community Service Instructor. Her helpers are April Adams, Noreen Jager, and Dorothy Hamil. Phone 934-.
- Kathy Mirsky is his physical therapist. She sees him once a month.
- He takes a lunch everyday. Usually 1 lunch bucket, 1 applesauce, 2 puddings.
- A communication book goes back and forth between home and Easter Seals everyday.
- He is put in "HIS" standing table everyday for 1 1/2 - 2 hours. He has own elbow pads to wear if he has short sleeve shirt on.  
"HIS" stander and tray kept at Easter Seals. It also has a pouch on it for his pump so that he can be tube fed water while he's standing in it.
  - They also work with him on using "HIS" Big Mac switch, which is a big round button that has a recorder in it. A message can be taped. When Dean hits the button then the recorder is activated saying a message like "I need some help", "Could I have some pudding please", or whatever he may be doing. It can also turn on a device (fan, radio, etc.)
  - Clothing: Always has spare change of clothes in his backpack and extra sets kept at Easter Seals. **Any soiled clothes are to be sent home.**

### **Helping Dean Move:**

- He won't bear any weight on his legs. Make sure you support his head.
- Before assisting Dean in any way, explain what is going to happen using a calm voice. This will reassure him and give him the chance to do whatever he can. Also, don't be rough when helping him.
- He has a total spinal fusion and his body doesn't /won't bend at all.
- If 2 people pick him up he tends to extend (stretch out) so be prepared. It's a reflex and he can't control it.

### **Temperature spikes:**

- In the past five years, Dean has had two periods of approximately six months each where he had periodic temperature spikes. Several doctors have tried to figure out what they are, BUT at this point, they don't know.
- It is not unusual for his temperature to be 104 or 105 degrees. Keep taking his temperature every 15-30 minutes. You should **NEVER** put a thermometer in his mouth. Only **1.** underarm **2.** ear **3.** rectal.
- You can put a cool sponge on his head, neck and body.
- His neurologist want his blood pressure taken during the pre-temp stage and after his temperature goes up.

- He carries HIS digital blood pressure machine in his backpack (outside zipper compartment) along with two extra strength Tylenol and a thermometer.
- After his temperature goes down, a few hours later, he'll be back to his regular self - eating as usual like nothing ever happened. His temperature does not go back up until weeks later.
- When it may happen again -?????????

**This is what you will see:**

- Dean will be droopy
- Labored / Erratic breathing
- He will shake all over with chills (may go on for 1-2 hours)  
THEN
- He will be very hot to the touch

**This is what you should do:**

- Try to contact Kathy to let her know
- Take his temperature **under the arm - ONLY** (in the beginning, it will be normal, but keep taking it every 15-30 minutes)
- Start giving water via tube
- Take his blood pressure
- Give him 2 Extra-strength Tylenol

**Money:**

Dean requires help in all financial matters. He does help to pay the bill when eating out when a waitperson gives the bill. Put the money in the bill in his hand --- when they come to pick it up, help extend his arm to give to the waitperson the money.

**Regarding Dean 's health concerns:**

You need to know that Diane , RN is Dean 's DMR Nurse who helps with his/her health concerns. Her phone number is 934-0000. Her address is Rt., Box, Georgetown, Delaware 19947. Contact after working hours by dialing 934-0000.

**Allergies:** Very sensitive to anesthetic agents and narcotics.

**Current Medications:** All medications are obtained from Happy Harry's at Long Neck  
Phone number: 945-0000

He takes his meds 1 pill at a time in a spoonful food – usually pudding.

The only liquid medication he'll swallow is bubble gum flavored thing otherwise he will just spit it out or it will run out of his mouth.

**DOCTORS/MEDICATIONS**

<b>Doctor, Address, Phone &amp; Fax Number</b>	<b>Prescriptions/ Medications</b>	<b>What It's For</b>	<b>Frequency of Visits:</b>
Dr. Linda - Family Doctor Phone Georgetown: 856-0000 Fax: 856-0000 Phone Lewes: 645-0000	- Signs Standing Medical Orders - Multivitamins - Flu Shots	Continue with good health.	Every year for physical and whenever he's sick.
Dr. - Dentist Fax/answer machine: 422-0000 Phone: 422-0000	- Cephalexin 250mg. 1 cap. 1 hr. before and 2 caps after dental work. - Diazepan 2mg. tab. Take 2 tabs 1 hr. before dental appt.	- Cephalexin: Preventive antibiotic because of so much metal in his body. - Diazepan: To relax him for appt.	Seen every 6 months for cleaning and check up.
Dr. - Podiatrist Phone: 945-0000 Long Neck Rd.			As needed to have his big toenail on his right foot cut.
Dr. – Gastroenterologist Kennedy Krieger Institute Baltimore, MD 21205 Phone: (410) 502-0000 Fax: (410) 502-0000 Contact: Debbie	- Propulsid 1 tab 15 min/30 min before meals. - Lactulose - Senokot - Bisacodyl Suppository as needed. - 2 Fleet enemas as needed.	Propulsid for reflux. - Lactulose, Senokot, Bisacodyl, and Fleet enemas for chronic constipation.	Yearly or as needed.

<u>Doctor, Address, Phone &amp; Fax Number</u>	<u>Prescriptions/ Medications</u>	<u>What It's For</u>	<u>Frequency of Visits:</u>
Dr. Sakubai – Neurologenetisist Phone: 9410) 502-0000 Barbara: (410) 502-0000		To try to determine Metabolic disorder	Seen every 6 months or as needed.
Dr. Milner – Ophthalmologist Limestone Medical Center Suite 217  Wilmington, DE 19801 Phone:			Seen every year to have his eyes checked.
Dr. Silberstein – Orthopedist Phelps Cerebral Palsy Treatment Center at Kennedy Kreiger Phone: (410) 502-0000			Seen annually or as needed.
Dr. William Neurologist Kennedy Kreiger Emergency night & weekend #410-502-0000 Day #410-502-0000 Fax # 410-502-0000	Lamictal Neurotin Phenobarb	Seizures	Seen every 3 mos.

## Other details about Dean's doctors who are specialists and health concerns:

**Dr.**— handles his seizure medication and seizure concerns. Dr. William will be working on following Dean's seizures & changing his medications.

**Dr.** - is Dean's new neurogenetisist. She is trying to find out if he has a metabolic diagnosis.  
-and temperature spikes if they reoccur.

**Dr.** - is his orthopedist who keeps track of Dean's past surgeries:

- spinal fusion
- bilateral hip reductions (twice)
- bilateral triple arthrodesis

He also gives orders for:

- wheelchair issues and special equipment
- prone stander and it's use (Right now for 1 1/2 - 2 hrs. daily)
- physical therapy

**Dr. Nancy** - his gastroenterologist follows him for:

- reflux
- chronic constipation

\*\* If there are any concerns between appointments with Dean not eating, vomiting, or having bowel or urine output problems, she needs to be called for instructions on what to do.

\*\*Dean was diagnosed in 1992 with Superior Mesenteric Artery syndrome which is not a problem now, but he should never lose a lot of weight or it could be.

\*\*Dr. Yokis writes prescriptions for all equipment in regards to Dean's G-tube.

\*\*He also has a gastrostomy 18 FR Mic-Key skin level gastrostomy 2.7 to be changed at least annually. Reorder # 0120-18-2.7

Change dates 12/09/99 by Kennedy Staff

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\*\*Right now, Dean must have:

- 2,000 cc's of water a day
- rate at which pump is set is 300

**Wheelchair Problems and Repairs/Special Equipment** - All repairs are done by Chesapeake Rehab. If there are any problems or concerns, call Kathy and she will follow up with Chesapeake Rehab.

Dean's wheelchair is a Quickie. Tilt in space, with washable seat covers. He got it 12/24/97.

Barrier Free Lift – is installed by Chesapeake Rehab in the ceiling of Kathy & Dean's home – Medicaid paid for the unit.

Bath Chair with reclining back

**Medical Supplies / Attends** - Obtained from American Home Patient 1-800-337-0000. This includes gastrostomy supplies. Ask for Barbara.

Order: 1 box extension sets (5) - every 3 months  
1 box 30 Ambulatory pump sets - every 3 months  
1 pkg. blue pads about every 3 mos.  
1 tube pkg. 2x2's non-sterile - as needed  
18 FR Mic-Key 2.7 skin level gastrostomy - as needed (There should always be 2 on hand, one at home and one in Dean's backpack on wheelchair).  
Attends - 2 cases special order: Attends size Medium #6707. (Dean also wears #1 Premium Pampers. The provider buys them at the store).

His 2 companion pumps are from American Home Patient in Salisbury MD. Phone# 1-800-337-0000.



## Personal Care Section

THIS IS TO ONLY BE READ BY PEOPLE WHO NEED TO HELP  
DEAN WITH HIS PERSONAL CARE.

### **His face:**

- Dean doesn't like having his face messed with so anytime you wash his face, brush his teeth, etc. expect the ticked off look.
- Don't take it personally he just doesn't like it.
- He's gotten a lot better - he used to fuss, but now it's just the look and sometimes he doesn't even do that.
- His left ear is always red and may have a sore from pushing back on it in bed and sometimes in his chair. Anytime it gets red, put Neosporin cream on it.

### **Turning him (right to left):**

- Always talk to him and tell him what you're doing and ask him to help.
- Guide his right arm up - you'll know he's helping when he turns his head to the left and his right arm starts going up (forward).
- Then roll him over - everything goes at once because of his spinal fusion.
- Be careful because he can roll back (check to make sure his left arm isn't stuck under his body).
- If his head is bent down and his legs are bent, he usually stays on his side.
- If he turns his head to the left when he's on his back, he's telling you he wants to turn on his left side.

### **Baths:**

Dean has his own elevated tub and uses a bath chair. He usually gets a bath in the tub Tuesday, Thursday and Saturday.

The way it's done at home:

- remember in the winter it is very important to have the house warm
- take Dean's clothes off
- put towel over seat of wheelchair before putting Dean in wheelchair
- get 1 beach towel, 2 smaller towels - 1 for on top of him after he gets out of the tub; 1 folded for a headrest and 1 folded and put over the right side of the bath chair at his hips -- as he pushes himself up on the side.
- fill tub with warm to almost 94°+ hot water put your arm in to check, then put Dean in the tub.
- usually a washcloth is put over his chest {everything else except his head is under water} and pour water over him for about 10 minutes so he has a good soak.
- wash his hair with Head and Shoulders shampoo
- he needs his eyebrows brushed - green toothbrush by tub - wet the brush and brush out any dandruff.
- wash face with soap - uses Dial soap - once you start with soap watch out as he can get soap on his hand and rub it in his eyes.
- then shave
- wash top to bottom - go slow and easy don't rush or he gets ticked off with soap and washcloth
- let water out and rinse with sprayer --- watch out not to get water in his face.
- drape towel over your chest and get Dean out of tub and into chair put towel over him and dry him off.
- **If you use the lift - no water can be in the tub before you put him in and all the water must be out before you take him out.**
- Blow dry his hair - be careful that it doesn't get to hot - there's a cooler button you press to take care of that. Blow-dry from the left side of his head.
- clean his ears with Q-tips after each bath
- his nails (fingers and toes) get cut every Saturday - his fingernails must be kept very short or he scratches his face/neck.

### **Teeth:**

- Use a soft bristled toothbrush and be patient.
- Use bubble gum toothpaste only.
- Dean will swallow the toothpaste and some may also come out of his mouth, so have something to wipe his mouth with.
- You have to hold his top lip up to brush his top teeth. (This isn't easy because he holds them together).
- Split his mouth into six sections and brush one section at a time.
- Between each section, give him time to swallow and calm down. If you don't, he will get frantic.
- Every once in awhile, he will bite down on the toothbrush. Just wait until he opens and continue.

### **Getting Dressed**

Shirt – pull over his head 1<sup>st</sup> and then put his arms through.

-arms- put his arm through the sleeve and then ask him to push – wait and give him time to do. He pushes his right arm through better than his left

-pant-put legs through – sometimes he may help push.

-roll from side to side to pull up his pants – don't forget to tell him before he rolls from side to side.

-shoes-loosen laces – all the way- PULL Tongue back

-when you take them off-same thing

-sock-you have to do completely

**Fingernails**- are cut every week w/reg. Fingernail clippers; must be kept very short or he'll scratch himself.

**Toenails**- cut w/fingernail clippers about every 2-3 weeks , all except his right great toenail which is taken care of by Dr. when needed.

### **Hair:**

Cuts

- He gets his stylish haircuts at Jan's Hair-Um about every 2 months. Jan knows him very well.
- In winter/bad weather, she will come to the house and cut his hair, but usually he goes to the shop in Lewes.
- Kathy trims Dean's hair every 2 weeks with his clippers.

Shampoo

- Dean uses Head & Shoulders for oily hair - no conditioner.
- His hair is washed every other day in the summer. In the winter, he may not need it as often.

Blow dry

- From his left side, blow down and back on sides.
- Make sure the air doesn't get too hot. There's a button to push which gives cooler air.

### **Shaving:**

- Be patient
- Uses both electric and disposable razors.
- When he has a beard, trim with electric razor everyday.
- Electric razor - Let him hear it on for a minute before you start. He'll grimace and throw his arms and then clam down when you get started.
- Disposable razor - You must be careful because he moves his head and at times may jerk it. Wash face with soap 1<sup>st</sup>. Use shaving cream. Watch out for him putting his hands up to his face and getting shaving cream on his hand. He may then rub his eyes and get shaving cream in them. If he gets shaving cream on his hands, wipe it off right away.

### **Bed:**

- Given to him by a family in 1991.

- Has full siderails that are padded.
- Has a 4" egg crate, which he buys with his money at American Home Patient whenever he needs to replace it.
- The head of the bed must always be elevated 30 degrees.
- Always use 2 bluepads over the egg crate (middle of bed) because usually 2-3 times a week he floods the bed.
- NEVER leave him alone on his stomach. He can move and get his head caught in the railings.
- Anytime he stays overnight there is a large blue foam wedge he sleeps on, so he's elevated when sleeping. If it's not at Kathy's house it's probably at Brian Bowman's.
- He usually starts out sleeping on his left side and turns on his back whenever he wants during the night.
- Don't forget---if he has a seizure when he's in bed he must be turned on his side.
- He has a TV Monitor & Voice monitor, so that the provider can be aware of seizures activity.

## Dean's Diapering Method

#1  
Using Small #1  
Premium Pampers

Criss Cross tapes as shown in #1 picture.

With tape up (away from Dean's skin) put penis into opening of diaper.

#2 Medium  
Attends  
Diaper #6707

The medium Attend with elastic waistband should be put on with tape placed down low so that the front of diaper can be folded down with elastic waistband folded over first then tape. Don't pull the front up tight or pull-tabs on the sides too tight.

#3

Final product should look like this.

Diapers - He must have his diapers changed on a regular basis with a unique diapering method. (See pictures) Always use wet wipes. He doesn't use powder.

### Dean's Weekday Routine

7:00 a.m. – 7:30a.m.	Rise & Shine. Gets dressed - he is used to having his socks, pants then shirt and shoes put on after he is in his wheelchair (put on in that order).
NOTE:	Eats breakfast and gets meds (Propulsid 10 min. before - other meds at end of meal). When you brush his teeth don't forget to brush a section at a time..
8:45 a.m.	Brush hair and wash face. Takes bus to Easter Seals. ( <i>Make sure Dean has at least 3 pairs of diapers in his backpack. Send in G-tube supplies. Send in packed lunch.</i> ) Make sure Communication Book is in his backpack.
9:00 a.m.	Arrives at Easter Seals.
3:00 p.m.	Bus leaves Easter Seals.
3:15 - 3:30 p.m.	Dean arrives home. He gets out of his chair and relaxes in bed.
6:00 p.m. – 7:00 p. m.	Check diapers. Gets out of bed. Start water via G-tube. Propulsid before dinner followed by water via G-tube/TV, other meds in pudding (If he gets a bath, it will be before G-tube).
10-11:00 p.m.	Brush teeth, wash face and then to bed. Charge feeding pump overnight. Dean sleeps in a T-shirt.

### Dean's Weekend Routine Saturday & Sunday

9:00 a.m.	Rise and shine, have large breakfast, meds (remember Propulsid <u>before</u> meal), get washed and dressed, etc. 1000cc's water after breakfast.
2-3:00 p.m.	Lunch on the run. Light lunch.
6-7:00 p.m.	Propulsid. Dinner (large one). Usually eats out. Start water again via G-tube 1000cc's.
8-9:00 p.m.	Meds with pudding and fruit.
Note:	*Take time during the day to give him his major bath, cut fingernails and toenails. This takes LOTS of time. <b>*GO-GO-GO on Saturdays (open schedule). {Spring-Summer-Fall} {Winter - inside things only}</b>

\*These times are while seizure medications are being changed they will change when he stabilizes.

**ESSENTIAL LIFESTYLE PLAN  
ACTION PLAN SECTION**

Action Plan	Person Responsible	Target Date Completion Date	Paperwork Required			Supported Learning Plan Required	
			Monthly Comments	Quart.		Yes	No
Live with Kathy where he feels safe and loved and keep close ties with his family.	Kathy Joy	12/01/00	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Have an active lifestyle - going out doing things in good weather.	Kathy Joy	12/01/00	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Make sure he gets his pudding at least two times a day.	Kathy Joy	12/01/00	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Make sure he's kept warm.	Kathy Joy	12/01/00	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Before helping Dean make sure you tell him in a calm voice what's going on and also give him a chance to do whatever he can for himself.	Kathy Joy	12/01/00	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Make sure Dean sees his doctors as needed: <i>Dr. Linda – Family doctor</i> <i>Dr. – Neurologenetisist</i> <i>Dr. – Gastroenterologist</i> <i>Dr. – Orthopedist</i> <i>Dr. – Ophthalmologist</i> <i>Dr. – Dentist</i> <i>Dr. – Podiatrist</i> <i>Dr. William - Neurologist</i>	Kathy Diane	12/01/00	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Make sure he has warm/hot bath using his bath chair.	Kathy Joy	12/01/00	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Listen to Dean and his means of communication.	Kathy Joy	12/01/00	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Go to Easter Seals CIL program.	Kathy Joy	12/01/00	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Keep his wheelchair, pumps, and specialized equipment in good working order.	Kathy Joy Diane	12/01/00	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Make sure his seizures are recorded.	Kathy Diane	12/01/00	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Help Dean with his money.	Kathy Joy	12/01/00	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>