

June 7, 2002

**Re: Patient Client**

**LIFE CARE PLAN UPDATE**

**INTRODUCTION:**

Patient Client is a 15 year-old Caucasian male referred by Mr. Attorney. The purpose of this referral was to develop a Life Care Plan to address the medical and non-medical disability lifetime needs and costs associated with his disabling conditions secondary to a 7/11/97 swimming accident, which resulted in C5 tetraplegia.

A Life Care Plan is a comprehensive report which addresses the medical and non-medical needs as a consequence of a catastrophic injury and which projects the costs of needed items and services over the person's anticipated life. These costs include replacement schedules and frequency of treatments. This Life Care Plan is specific to the individual and not generalized to a particular disability.

This Life Care Plan was prepared by a review of the medical records provided, in-person interviews with Patient and his parents, and consultation with his treating physicians.

An initial nursing assessment interview was conducted at the Client home on 8/7/00 in the evening. I met with Patient and his mother who provided most of the information regarding his medical history, current status, and equipment and supplies. His father was also present briefly as was his 18 year old sister who seems very protective of him. Patient is a large teenage boy who presented in shorts and a T-shirt. He was in bed when I arrived, though he and his mother were able to demonstrate the equipment they use and transfer techniques. He was somewhat quiet and reserved, only offering information upon request. His mother was the primary source of information.

Patient lives in a split-level home and is maintained on the first floor. His room is too small to fit all of his equipment and his bathroom is inadequate for him to use, therefore he uses an inflatable in the bed bath mattress for bathing and for his bowel routine. The Client's are planning to purchase a ranch home, which is in the neighborhood and plan to modify that home so that Patient will have adequate space and will be able to maneuver better with his wheelchair in his living environment. His parents envision him being able to live there for life with attendant care assistance even when they are no longer available to care for him.

On 5/10/02 I traveled to the Client home to perform an updated nursing assessment. Patient was asleep in bed after a long day at school, but I was able to get updated information from Mr. and Mrs. Client. Updated assessment data is referred to in the body of this report and in the appendices.

## **MEDICAL HISTORY:**

Patient was 12 years old on the date of the accident. He reportedly had jumped off a jogging trampoline into four feet of water when he hit bottom and hyperextended his neck. He was submerged for an unknown period of time. He was pulled out of the pool and was initially pulseless and not breathing. Basic life support was started by laypersons at the pool. When EMS arrived he was awake with shallow respirations. Ventilations by mask were started and his mental and respiratory status improved. His cervical spine was stabilized by EMS and he was transported to the Jersey Shore Medical Center. On arrival he was awake with a Glasgow Coma Score of 15 (the best). He was intubated due to continued respiratory distress. Cervical CT scan showed a fracture of the C5 body at the right lamina and left facet. CT of the abdomen and pelvis showed positive consolidation of the right posterior lung base and an incidental finding of a right renal cyst. He was started on Solumedrol infusion (steroids) after a bolus of Decadron (steroid) in the ER. He was placed on mechanical ventilation and a Dopamine (blood pressure support) infusion. He was also given Fentanyl (for pain) and Versed (sedation) as needed. He was air transported to Children's Hospital in Philadelphia that afternoon where he was further stabilized and then transferred next door to the Hospital of the University of Pennsylvania for surgical stabilization.

An emergent C5 corpectomy and ileac crest bone graft with fusion and plating was done for the C5 burst fracture by Dr. Marcotte. He was placed in halo traction. On 7/17/97 he had gastrostomy and jejunostomy (small intestine) tubes placed for the purpose of enteral (gastrointestinal) feeding. He also had a tracheostomy tube placed due to the need for longer-term mechanical ventilation. He was weaned quickly from the ventilator to a trach collar (mist and oxygen as needed to the trach opening). Staph aureus and strep pneumonia infection (bacteria that cause pneumonia) were found in the lungs and trachea and he was treated with Ancef, an intravenous antibiotic. He initially was started on J (jejunostomy) feeding which he tolerated with some diarrhea. He was then switched to G (gastrostomy) tube feedings which he was initially unable to tolerate. A gastric emptying study was done and showed no obstruction. The feedings resumed at a slower rate and he was discharged from HUP tolerating clear liquids. Functionally upon discharge, he had no distal function in his wrists or hands and he had no lower extremity function. He was discharged on Trazadone for depression, Colace and Dulcolax suppository for his bowel program, Ancef for respiratory infection, Iron for anemia, and Erythromycin, an antibiotic to help gastrointestinal motility. He was transferred to Children's Specialized Hospital on 7/28/97 with halo traction intact.

Upon admission to Children's Specialized Hospital he was found to be in spinal shock with an ASIA (American Spinal Cord Injury Association) level of C5 complete at the motor level and T4 complete at the sensory level. He had some elbow flexion and extension bilaterally with trace shoulder movement. The following describes his rehabilitation course by systems.

**Respiratory:** He was transferred with a #4 Shiley trach in place and this was increased to a #6 due to his inability to manage his secretions. On 8/22/97 his tracheostomy tube was plugged and it was able to be removed on 9/9/97.

**Cardiovascular:** He had periods of autonomic dysreflexia during his stay which can result in periods of dangerously high blood pressure. These episodes occurred during his bowel and bladder program. He initially could not tolerate sitting upright due to hypotension or a drop in blood pressure. On 8/26/97 he was started on Sodium Chloride to increase his blood pressure. His lower extremities were wrapped to promote venous return of blood and an abdominal binder was used for the same purpose. He was then able to gradually tolerate positional changes. His central line (Broviac catheter) was removed on 9/5/97. He had some electrolyte abnormalities due to episodes of vomiting and an EKG was performed on 9/23/97. It was within normal limits.

**Metabolic status:** On 9/19/97 he developed nausea and vomiting and was unable to take fluids. He was clinically dehydrated and had acute hypercalcemia (too much calcium in the blood, can cause cardiac arrest). This was attributed to his spinal cord injury and immobility which can lead to bone loss. He received intravenous fluids from 9/19/97 to 9/26/97. He received steroids including a bolus of Solu-Medrol and then hydrocortisone for 24 hours on 9/22/97. Patient was put on Calcitonin (calcium regulating hormone) from 9/22/97-9/30/97 and this increased his nausea but did control his calcium levels. He continued with an elevated calcium level upon discharge, though was not symptomatic.

**Infectious status:** He had ongoing urinary tract infections during his stay at Children's Specialized Hospital. He had four infections and was treated with Bactrim DS for 30 days. He did have a urologic evaluation on 10/20/97 with Dr. Stoneham. He was found to have a hyperreflexic neurogenic bladder and recommended a cystometrogram. This was done on 11/21/97 and he had a low resting pressure. He was put on Ditropan four times a day for this problem. A cystogram on 10/9/97 revealed no reflux. His bladder ultrasound revealed a residual of 182 cc and his kidney ultrasound was normal.

**Gastrointestinal status:** He was treated for neurogenic bowel and decreased intestinal motility with Colace and Senekot. He was also started on Cisapride and Zantac for slowed gastrointestinal motility. An abdominal x-ray on 8/16/97 revealed retained fecal matter and enemas were ordered. A repeat abdominal x-ray on 9/19/97 was normal. He was seen by gastroenterologist Dr. Winzelberg who thought that he had gastroesophageal reflux and recommended Prilosec, Propulsid, Tigan suppositories, and medical follow-up.

**Orthopedic status:** He had the halo in place upon admission. He had his C-spine films reviewed by Dr. Sanderson who felt that the screws and plate were in place. Dr. Marcotte at the Hospital of the University of Pennsylvania removed the halo on 9/2/97 and placed him in a Philadelphia collar. A spine x-ray on 9/9/99 revealed that the plates and screws were intact. He complained of right shoulder pain but an x-ray was normal.

**Psychiatric status:** Upon admission he was receiving Trazadone for depression. He was weaned from this medication and put on Prozac for a continued depressed mood. This was discontinued on 9/19/97 when his mood swings were attributed to his hypercalcemia. He was seen by psychiatrist Dr. Boregowa on 10/23/97 and he was found to have an adjustment disorder with depressed mood and ordered Wellbutrin. He had a somewhat improved mood after that.

**Speech/language:** Testing of Problem Solving was equal to premorbid results at school which showed an impact due to a learning disability. Speech therapy focused on mealtime supervision and airway protection due to weak cough. They worked on using incentive spirometry and developing his head, neck, and shoulder muscles.

**Gross motor:** Physical therapy worked on tolerance to upright seating and he was able to sit upright at 30-70 degrees in his power wheelchair. He was independent with shower chair mobility in the hospital and for short distances in the community. He was able to initiate rolling a manual wheelchair but needed moderate to maximum assistance with this. He required full support to sit upright at 70 degrees.

**Fine motor:** He presented with a full passive range of motion of bilateral upper extremities at the time of discharge with the exception of finger extension which was allowed to become tight to allow for tendonesis action with active wrist extension. He was able to use tendonesis action of his left wrist to pick up a one inch cube. He was able to independently operate a power wheelchair to negotiate his environment using a Joystick with his right hand, a joy stick goal post attachment, and extension for the toggle switch. He had demonstrated the ability to control items such as a fan, light switch, and Nintendo using a variety of remote switches. He was unable to functionally propel a manual wheelchair at the time of discharge. He was able to access a keyboard for typing on the computer with minimum to moderate assistance from the therapist and set up with adapted typing aid on his right hand. He was dependent for set up of feeding including donning a universal cuff. He was able to use the sandwich holder if another person set it up and was available to reposition the sandwich. He required maximum assistance to drink with a straw and cup. He was able to deliver a spoon to his mouth with occasional assistance and needed moderate assistance to load the utensil. He required maximal assistance to don a T shirt and was dependent on others for dressing. He required moderate assistance at the elbow after set up to wash his face using a hand mit. He utilized minimal assistance/contact guard to brush his teeth with support at the elbow and adaptive equipment. He was dependent for all aspects of bathing and grooming at the time of discharge.

**Rehab tech/equipment:** A Hoyer lift and hospital bed with alternating pressure mattress were recommended and delivered. Environmental control units were recommended and the family was to seek funding. A manual and power chair were ordered. A book holder, inflatable bed bath, and overhead table were ordered. An evaluation was done for a computer and alternate access joy stick so that Patient could take notes at school and a foundation agreed to fund it. He was discharged with bilateral AFO's and cockup hand splints, Coude catheters #12 French, multi-podus boots, abdominal binder, ace wraps, wash mitt, universal cuff, sandwich holder, and scoop dish with extended straw. A tilt table was on order.

**Discharge plans:** A home health aide was recommended at the time of discharge. He was to have outpatient physical and occupational therapy three times a week. He was encouraged to become involved in school activities and to join the Spinal Cord Support Pen Pal Program. He was to have continued psychotherapy.

Patient was discharged to home care services. He also received in home school instruction at first until his Philadelphia collar was removed. He was eventually mainstreamed at school and a computer was ordered for him to take notes and do school work. Patient developed severe spasms of his lower extremities and by 12/27/99 he was referred to Dr. Deutsch, a neurologist. Patient had developed shaking like movements in his legs as well as spasms of his stomach which he described as a tightness. He was found at that time to be ambulating with a power wheelchair. He required assistance for

transferring, eating, and dressing. He was assisted with straight cathing himself for residual urine every four hours but occasionally had bouts of incontinence. He also was on a bowel program. Another physician had tried Klonopin and Baclofen for the spasms for 2 ½ month trials with no change in his symptoms. He was currently attending physical therapy and occupational therapy at school and at the Life Center every Thursday. His list of medications included Dulcolax, Ditropan, and Elavil. He had continued with frequent urinary tract infections at this time. His spasms were felt to be due to clonus (tremors) and hypertonicity (increased tone) in the lower extremities. He was to try Zanaflex twice a day and he was to decrease his Elavil.

In January of this year he developed left lower lobe pneumonia. He was in Brick Hospital for ten days and was found to have a positive sputum culture for pseudomonas. He was placed on IV antibiotics and was transferred to Children's Hospital of Philadelphia due to a deteriorating pulmonary status on 1/27/00.

On the day of admission to CHOP (Children's Hospital of Philadelphia) he began to have an increased work of breathing and increasing oxygen requirements to maintain oxygen saturation levels. He was started on BiPAP which is a machine which provides airway pressure and was admitted to the Pediatric Intensive Care Unit.

Upon admission his pulse oximetry was 96% on 15 liters of oxygen by non rebreather mask. He was alert, well hydrated, and well nourished. His chest had poor air entry diffusely with some crackles heard on the right. He had a large decubitus ulcer in the sacral area due to improper wheelchair seating. His lower extremities were flaccid with no motor or sensation. His upper extremities had limited motor control. His blood count showed an elevated white count with 4 bands indicating bacterial infection. A chest x-ray showed a left lower lobe infiltrate.

Patient was transferred from the ICU to the pediatric floor on 1/31/00. He was on respiratory treatments of Mucomyst, Albuterol, and Pulmozyme. He also was receiving chest physical therapy and a coughlator which is a device to assist his cough. He was gradually weaned from the oxygen and at the time of discharge he was on a minimal amount of oxygen by nasal cannula. He was to maintain his oxygen saturation at home to 95% while awake and 93% while asleep. Chest x-rays demonstrated clearing of infiltrates.

Patient has had several hospitalizations since the initial life care plan report. Below is a description of those interim hospitalizations.

### **3/13/01-3/18/01 Discharge summary from Meridian Health System**

He presented with a positive blood culture from the ER of gram negative bacillus and spiking temperatures despite oral antibiotics. He was admitted for intravenous hydration and intravenous Rocephin. The medications were continued and the culture grew back E coli which was found in the urinary tract. He gets intermittent catheterizations. Of note, a kidney stone was found and will be dissolved by Dr. Rotoloin in one week. He will be placed on Cipro and will have an infectious diseases consult with Dr. Kleinfield.

### **3/22/01 Report of procedure Meridian Health System**

**Surgeon:** Dr. Rotolo

**Diagnosis:** Right ureteral calculus.

**Procedure:** Cystoscopy and right retrograde pyelogram, fluoroscopy, ureteroscopic laser lithotripsy, and double J stent insertion.

**Indications for the procedure:** The patient is a 15 year old C4-5 quadriplegic with a recent episode of sepsis due to a urinary tract infection. An intravenous pyelogram demonstrated a large stone in the distal right ureter.

### **5/5/01-5/8/01 Discharge summary from Meridian Health System**

**History of present illness:** The patient is a 16 year old white, quadriplegic who presents to the ER in urosepsis. High fevers of 103-104, shaking and chills. He recently had a stent placed for a stone in the left ureter.

**Hospital course:** He was restarted on Cipro before coming to the ER. Still running temperatures of 103-104. Cultures were negative but he had two doses of antibiotics before the cultures. He was placed on Rocephin and was afebrile in 48 hours. He was encouraged to drink more fluids. He was seen by Infectious Diseases and Urology. He is to have the stent removed in two weeks. He is to remain on medications and to increase his fluids and continue straight cath as necessary by family at home. He was discharged on Cipro 500 mg twice a day. He will remain on this until the stent is removed and cultures are taken post stent removal.

### **9/19/01- 9/21/01 Admission to Jersey Shore Medical Center**

**Chief complaint:** Open wound to the sacrum.

**History of present illness:** The patient is a 15 year old male who is a C4-5 quadriplegic status post a diving accident 4 years ago. He was treated at the University of Pennsylvania with a spinal fusion and tracheostomy as well as a PEG tube and he recovered well. Roughly two years ago he developed a sacral decubitus ulcer and since that time has been treated with conservative therapy and wound packing. He is now being admitted for debridement and wound closure.

**Plan:** Admission, debridement and closure, placement on Clinitron bed as well as drain placement, need for long term antibiotics with PICC line placement as well as infectious disease consultation.

**Report of operation:** Surgeon- Dr. Godek. Debridement of sacral decubitus, preparation for flap surgery with osteotomy. Bilateral gluteus maximus myocutaneous muscle flaps.

### **PRESENTING PROBLEM:**

Patient incurred a C5 complete and permanent cervical injury. He has no sensation below the nipple line and has motor control to the bicep with wrist extension only with adaptive devices.

Patient is not independent in transfers, turning, or positioning in bed, though he can provide some assistance. He is able to accomplish weight shifts to prevent edema and

skin breakdown by using the recline mechanism of his power wheelchair every 30 minutes throughout the day. He also has a Rojo cushion to redistribute pressure to his sacral area. He currently sleeps on an Invacare alternating pressure mattress. He is now in a Clinitron bed until the end of the summer to prevent further skin breakdown in his sacral area now that he has had a muscle flap procedure. Patient's mother is currently the one who is responsible for turning and positioning while in bed. Forty hours a week of home health aide service is now funded through the state through Medicaid.

Patient currently cannot perform his personal care and is total assist for bathing and dressing. He can perform some grooming and feeding activities with set up and adaptive equipment but requires supervision and moderate assistance with these activities. He cannot don his braces or splints without maximum assistance. He needs total assistance with his bowel and bladder programs. He is independent in power mobility but is dependent at this time on manual wheelchair propulsion, though his mother states that he can do it for limited distances in therapy.

His bowel program consists of a Dulcolax suppository daily to promote peristalsis and manual disimpaction as needed by his mother. He is intermittently catheterized with a straight catheter every four hours. He is to have a suprapubic catheter inserted at Children's Hospital which will decrease the incidence of urinary tract infections and promote more independence. This catheter will need to be changed monthly by skilled nursing. Patient has had problems in the past with frequent urinary tract infections and has been on antibiotics intermittently. He is also on Ditropan for his neurogenic bladder. He is to have urological follow-up every six months at Children's Hospital which will include urinalysis and urine cultures. He may also need this testing more frequently when he is symptomatic for a urinary tract infection. He will also require yearly urological testing such as a cystogram and renal ultrasound or renal scan. Patient has urinary incontinence despite the Ditropan between catheterizations. As of May, 2002, Patient has had continued urological difficulties including admissions for urosepsis and renal stones. Because of his urinary difficulties, he is now being followed by the urologist more frequently. He has periodic need for oral Cipro or intravenous Rocephin for urinary tract infections. The plan is still for placement of a suprapubic tube to decrease the chance of infections.

Patient has had a significant problem with muscle spasms of his lower extremities. These are worse when he is lying down but do occur also when he is in a wheelchair. He describes these episodes as painful and embarrassing. I was able to observe these spasms which occur spontaneously and consist of shaking and movement of his legs over which he has no control. Patient has been on various oral agents for this condition and they have only partially controlled his symptoms. Uncontrolled spasticity can limit activities of daily living and also contribute to the formation of such conditions as pressure sores and pneumonia. Contractures can also occur which can lead to significantly decreased mobility and the need for orthopedic surgery. Patient is considered to be good candidate for the Baclofen Pump which would deliver this medication directly into the fluid surrounding the spinal cord via a catheter in small, precisely controlled doses. This has been found to be more effective and to reduce side effects of oral Baclofen which can

include kidney and liver damage. The medication is replaced monthly and the pump itself is changed every 4-5 years when the batteries run low. Patient will soon have a trial done at the office of Dr. Novembre, a pain management specialist who was referred by neurologist, Dr. Deutsch. This trial has been on hold but is still a consideration for the future.

Patient currently has a significant decubitus ulcer in his sacral area which was caused apparently by improper seating in his wheelchair. The seating issue has been corrected but this wound has not healed in two and half years and requires daily wound care with skilled nursing visits every two weeks inspect the area and assess effectiveness of the wound care regimen. I measured the wound during my initial nursing assessment and it is approximately 1 inch x 1 inch with a depth of 1 inch at the area of the sacrum. The wound has pink granulation tissue and is draining moderate to large serosanguinous drainage without odor or other signs of infection. The current wound care regimen is to cleanse the area with normal saline then pack with ½ of a Kaltostat pad (a special dressing which promotes moist healing and tissue repair) and then normal saline wet to dry dressing on top (which promotes debridement when removed). This is done every three days, however, due to drainage and soiling from fecal contamination and urinary incontinence this area must be redressed with a clean top dressing daily. Often Patient's mother ends up changing the entire dressing more often due to the need to keep the area clean. Dr. Clark has projected that if this area does not heal, he will need plastic repair with a skin flap. As of May, 2002, the area is now completely healed post flap procedure. He now longer requires wound care to the area. He will continue to require a Clinitron bed until September of 2002.

Patient has had frequent upper respiratory infections and required hospitalization for severe pneumonia last winter. He has home equipment such as a Coffalator (machine to assist coughing) and mini-neb equipment for episodes of respiratory distress. He now receives these respiratory treatments on an as needed basis but will require the continued rental or purchase of this equipment to prevent further episodes of life threatening pneumonia. His mother provides chest physical therapy treatment and encourages coughing and deep breathing as needed and he still uses home oxygen as needed for shortness of breath and other episodes of respiratory distress. Patient does need assistance to cough and clear secretions due to paralysis of the intercostals muscles. His pulmonary condition is monitored by Dr. Friedman of Shore Pulmonary locally and by Children's Hospital for periods of hospitalization due to pneumonia.

Patient has had problems in the past with gastroesophageal reflux and had been on medication for this condition when he was discharged from Children's Specialized Hospital. He is no longer on this medication but is seen twice a year by Dr. Winselberg, a gastroenterologist. He may require this medication again if reflux continues to be a problem as it can be a cause of aspiration pneumonia and swallowing difficulties.

Patient is now being seen by Dr. Folkman, a physiatrist at Stone Rehabilitation. She has recommended an evaluation at Kessler Rehabilitation for therapy needs. This team evaluation was completed on 5/16/02 and no additional therapy needs were seen at this

time. Patient had been having shooting pain in his neck with numbness in his upper extremities. This has resolved. He is due to be followed by neurosurgery to assess his fusion.

### **PHYSICAL LIMITATIONS:**

Patient has only limited use of his upper extremities and must use adaptive devices to turn pages in a book, write, or use his laptop at school. Patient will continue to need computer equipment for both home and school with the necessary adaptations so that he can pursue educational, avocational, and future vocational activities. He is able to self feed with adaptive equipment but still requires set up and assistance with supervision. He is independent in power wheelchair mobility but is still working on manual wheelchair mobility which he can propel for short distances indoors. A manual wheelchair is needed as back-up in case the power wheelchair requires repair..

Patient is totally dependent on others for bathing, dressing, turning and transfers. Transfers are accomplished with either the Hoyer lift or the Easy Pivot devices in his home. He is currently bathed in bed as the bathroom in his room is inadequate for fitting a roll in shower wheelchair or even a commode at this time. He cannot stand without the assistance of a tilt table. At present he does not have a standing frame or tilt table at home but does work with these at physical therapy. Weight bearing in spinal cord injured patients is essential to prevent osteoporosis. Patient wears bilateral AFO's for support of his lower extremities while in the wheelchair. He wears sheepskin lined Multi-podus boots at night to prevent skin breakdown. He has bilateral long opponens splints to assist with the use of adaptive devices on both upper extremities.

Patient's morning and evening routines are extensive due to the assistance needed to accomplish his routine activities of daily living, bathing, bowel and bladder routines, wound care, and any necessary respiratory treatments. These routines average 2-3 hours each morning and evening. He also requires assistance with intermittent catheterizations throughout the day. Patient is up in his wheelchair from the morning through school into the evening when he usually goes to bed after dinner to watch some TV. Patient has been attending school through the summer as well to catch up on some courses. He attends physical and occupational therapy through the school with supplementation at the Life Center one day per week. During the summer he attends the Life Center for physical and occupational therapy three days per week.

Ongoing complications include urinary tract infections, renal stones, respiratory infections, skin breakdown with a sacral decubitus now status post muscle flap, severe bilateral lower extremity spasms, and gastroesophageal reflux. He has had only two episodes of autonomic dysreflexia at home but due to the life threatening nature of this condition he will require skilled supervision of his bowel and bladder program for life should his mother not be available. Provisions in the life care plan remain for some additional supportive counseling for adaptation to disability.

### **ENVIRONMENTAL INFLUENCES:**

Patient does not perspire below the level of the lesion and he requires constant monitoring. Overheating can lead to autonomic dysreflexia and cold can lead to an increase in muscle spasticity. He does best in a regulated indoor environment which is set for 70 degrees.

#### **CURRENT MEDICAL CARE:**

Patient's primary care physician is Dr. Clark who sees him every 2 months. He coordinates medical treatment, prescribes necessary medications, and oversees him pulmonary, wound care and bowel and bladder programs.

Patient is followed locally by Dr. Rotolo for urological care but his case has now been referred to Dr. Canning at Children's Hospital of Philadelphia for insertion of a suprapubic tube. Dr. Canning will also order diagnostic testing and see Patient 2-3 times per year. As of May of 2002, Patient is seen every three months by Dr. Rotolo due to the increase in urinary tract infections. The plan is still to ultimately place a suprapubic tube.

Patient is seen by neurologist Dr. Deutsch for pain and spasticity management. Dr. Deutsch manages his oral medications for this condition and has referred him to Dr. Novembre for implantation of the Baclofen pump. Dr. Deutsch follows him every four to six months.

Patient is followed locally by Shore Pulmonary on an as needed basis and is followed acutely by Children's Hospital of Philadelphia for severe respiratory infection.

Patient is seen by Dr. Winzelberg at Children's Specialized Hospital twice a year for gastrointestinal evaluation.

Patient has not been back to see Dr. Marcotte, the neurosurgeon at the Hospital of the University of Pennsylvania for follow-up of his spinal fusion. He should be seen every 1-2 years to evaluate the status of the hardware.

Patient has not been followed yearly by physiatrist Dr. Diamond for coordination of his spinal cord rehabilitation program. This is recommended by the National Spinal Cord Institute for coordination of his rehabilitation program and equipment needs. He should also have a therapy team evaluation at the same time yearly. Patient is now being followed by Dr. Folkman and had had a team evaluation at Kessler Rehabilitation on 5/16/02. This report is pending.

Patient is not currently seen by a podiatrist and this is recommended in the life care plan to address issues of the lower extremities.

Patient receives skilled nursing visits every two weeks to assess his wound healing. This will continue as long as he requires wound care. He has been referred to a Wound Center

for evaluation of surgical skin flap closure of this wound. Skilled nursing needs remain in the life care plan for his bowel and bladder program.

Patient is seen by a psychologist once or twice a month. His family has not yet attended family counseling but recognizes the necessity of this at times of crisis.

Current medications include:

1. Zanaflex 4mg taken three times per day for spasticity.
2. Ditropan 5 mg three times per day for neurogenic bladder
3. Dulcolax suppository daily for bowel program

At any given time Patient may be on Albuterol mini neb treatments for his respiratory status, medication for gastroesophageal reflux, and antibiotics for urinary tract infection. An allowance has been provided in this Life Care Plan for medications beyond his current usage based on the frequency with which he has needed these medications in the past.

## **EDUCATION AND TRAINING**

Patient is in 12<sup>th</sup> grade this year. A review of Patient's Individualized Educational Plan reveals that he has been monitored by the school since 1992 for a learning disability. He does receive additional classroom support related to this pre-existing learning disability in math and science. He is also for assistance now due to his physical disability. He requires a wheelchair accessible classroom and the use of specialized equipment. He must have access to the school nurse at all times for catheterization and other health related issues including the risk of autonomic dysreflexia. He is now receiving physical therapy and occupational therapy services through the school.

Patient was evaluated in 1999 by United Cerebral Palsy for assistive technology issues. Patient at that time was proficient in using the keyboard of his laptop computer and a joystick mouse with the typing peg in his right hand. There were concerns about his carrying the joystick mouse back and forth to school and it was recommended that one also be purchased for school use. He must be able to use the computer on battery power and this should be replaced every two years. He also should have a power surge protector and grounded extension cord for when he has to plug in. He needs access to a printer at home so that he can carry his work home on a floppy disc. He will need Microsoft Word and Office which are the software used at school. He will also need anti-virus software as he uses the Internet at home for research. He also should have a well padded case which can carry his laptop and his school papers. At present Patient uses Dragon Dictate but if he upgrades to Dragon Naturally Speaking he should have more memory and a faster processor.

In conclusion, Patient will need to have access to computer technology and the Internet to maximize his educational and vocational potential. At the age of 21 he should be referred to the Office of Vocational Rehabilitation for continued assessment of his vocational

potential, counseling, and referral for assistive technology. A private vocational evaluation is also recommended to coordinate these efforts and make recommendations.

### **SOCIOECONOMIC STATUS:**

Patient's primary health insurance is through his parents. Patient's parents both work during the day. Ms. Client works at Brick Hospital until 5:30 PM most nights. As of May 2002, Mr. Client is now home with Patient and is providing home health aide care funded by the state. Mr. Client has received home health aide certification. He has an 18 year old sister and an 11 year old brother. They live in a split level home which is inadequate to meet the needs of a wheelchair bound individual. The family has plans to move to a ranch home down the street and to modify that home. This Life Care Plan includes the modifications necessary to provide the environment for Patient most likely to promote independence and ease of care. The family envisions that Patient will occupy half the house and will have his own bedroom/ bath combination so that he can live there as independently as possible even after his parents are gone.

### **PSYCHOSOCIAL/BEHAVIORAL:**

Patient presented as quiet and somewhat shy. His mother did most of the talking though Patient did interject some information. He was also cooperative and polite. The family unit is supportive and seems to take his disability in stride. His sister exhibited warmth and caring towards him during our interview and was concerned about what he wanted to eat while she got take out for the family. Despite this strong family unit there are the everyday stressors of making a living and raising three adolescents as well as the added stress of coping with a child with a disability. I have included family counseling to assist this family where needed with adapting to Patient's disability and planning for his future needs.

Social outlets for Patient include school activities. His main interest is baseball cards and he has trouble holding them or sorting them due to his disability. He would like to get software that could maintain his collection electronically. He also uses the Internet but is not yet hooked up to the various resources and support groups that are available. He also would like to know more about other activities he can engage in with his wheelchair and I have recommended that a therapeutic recreation evaluation be included in his yearly spinal cord center evaluation. This will foster hopefully a sense of belonging and decrease the isolation he must feel in his mainstreamed environment at school.

Patient gets along well with his teachers and peers according to his Individualized Educational Plan. He has not presented any behavioral problems at school.

### **CONCLUSIONS:**

Careful consideration has been given to all the medical, rehabilitation, and evaluation data within this file. Patient Client has incurred significant handicapping conditions secondary to his C5 tetraplegia. It is reasonable to assume that he will continue to require

support and necessary outlets to allow for an ongoing adjustment to disability. Therefore, counseling support is important for Patient and his family. Patient requires and extensive Life Care Plan for long-term support and maintenance. The primary focus of this Plan is to reduce complications and to provide Patient with quality of life. Because he is now three years post-injury, there will be no further significant improvement though he will still require rehabilitation services to maintain his abilities and prevent complications.

The spasticity problem has reduced his quality of life and will require life long treatment. He will either receive oral medications or require an intrathecal Baclofen pump. The Baclofen pump has the potential for better control of this condition with fewer side effects. The information regarding costs associated with the Baclofen pump will be addressed in future aggressive medical procedures. If he continues with the pump for spasticity management then the cost of the anti-spasticity medication will be replaced by the monthly cost of refilling the Baclofen pump. This will be further explained in the appendices.

Patient also has a significant sacral decubitus ulcer which is likely to require surgical intervention as it has not closed in two years. This area requires daily wound care and the services of a skilled nurse. He is also at risk for sepsis which could be life threatening should this wound not heal. As of May 2002, this has been surgically repaired and is healed. He remains on a Clinitron bed until September of 2002.

Patient and his family have been managing fairly well with the assistance of Meridian Home Care. There have been problems finding a consistent caregiver. He requires home health aide service with an LPN/RN to visit daily to perform his bowel routine. Around the clock care is required because he cannot turn himself in bed independently and will be at risk for further skin breakdown. He will also need a skilled nurse to change his suprapubic catheter monthly and to inspect his skin for further breakdown and institute skin care measures. A home health aide by state law cannot perform the bowel routine, suprapubic catheter changes, or complex wound care.

There is provision in this life care plan update for additional annual hospital days based on the last two years. Patient was in the hospital 30 days in 2000 and 11 days in 2001. For the purpose of providing acute care needs related to potential complications related to Patient's quadriplegia, an allowance of 15 days per year has been projected.

The present and future needs dictated by the onset of his injuries are outlined in the attached appendices and are based on projections of present and future care needs. All of the costs contained within are based upon an anticipated normal life expectancy of 60 years (60.19) remaining as per the U.S. National Center for Health Statistics, Vita Statistics of the United States 1993 life tables. Life expectancy projections for Patient Client will need to be obtained from his treating physicians.

Please note that all costs reflect market prices and do not include sales tax, shipping, or handling. No adjustments have been made for inflation. All growth trends need to be determined by an economist.

Pending receipt of additional records, this Life Care Plan is subject to amendment.

Respectfully submitted,

Valerie V. Parisi RN CRRN CCM  
Certified Rehabilitation Nurse  
Certified Case Manager

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