

PATIENT EDUCATION QUESTIONS

10/22/14

**1) How do I maintain a positive attitude in the face of a major medical setback?
How do I cope with the uncertainty of the future and what are various coping strategies in general?**

Patient reported "I keep my regrets to a minimum about my life". "I take one day at a time". Participating in activities that "I was previously involved in but now I just do adapted versions of them." "Focus on what you can do." Maintain activities and an active lifestyle. Be proactive about your health. Have and set future goals. Look at around and others, making social comparisons can help you realize that you are often better off than others and that others are struggling with the same things that you are dealing with. Get involved in recreation programs and get involved with others. Mentor others.

2) What are my discharge options if I can't go home? Who can help me?

Get in touch with case workers and social workers whom can help you. Skilled facilities can be utilized for longer hospital stays after procedures. Veteran homes can help meet long term care needs, but have waiting lists. Because of this planning is important and getting your name on a waiting list can be important. Coverage can depend on service connectedness status so it is important to again check with your case manager or social worker if you are not familiar with your status. Think ahead if your care needs are going to change, as forward planning can make transitions much smoother and less stressful.

3) How is a patient evaluated whether they can walk? What are other options for mobility?

Assessment of lower limb strength is important, especially your gluteal muscles (buttocks). The buttock muscles are needed to help stabilize your body for standing. Your age and secondary medical conditions are factored in as well. Evaluation for walking is done on a case by case basis so that appropriate walking goals are established, correct equipment is utilized and safety is optimized while risks are minimized.

4) What is the best way to get my house ramped and what are other means for me to get in and out of my house?

If you live no more than 1 hour away from the VA, an occupational therapist can visit your home to complete a home evaluation. There may be restrictions on ramps that interfere with

sidewalks or other environmental factors. Porch lifts are another option instead of ramps due to limited space to install a ramp. Vendors can also be sent to your home to evaluate for home access. It is important to have two exits if possible (egress and ingress) for emergency situations. Home Improvements and Structural Alterations (HISA) grant funds can be sought for home modifications and HISA is a one- time grant. It is usually necessary to get three competitive bids and you will be responsible to pay for work that exceeds moneys obtained from HISA funds.

5) What will help me increase my functioning after heterotopic ossification (HO) surgery?

Not everyone with spinal cord injury gets heterotopic ossification. It is a condition where extra bone gets laid down. It can be painful and can restrict joint mobility. Treatment can include; Medication, radiation and surgery. Surgery is for more extreme cases and is usually avoided if possible due to bleeding, HO can reoccur. It is important to keep joints as functional and mobile as possible if HO occurs.

6) What is the best way to heal my wounds and what will prevent them from spreading?

Persons with Spinal Cord injury are prone to pressure sores. The skin changes with aging. These changes include loss of skin elasticity, thinning of the skin and separation of the layers. All these changes effectively weaken the skin. Persons must recognize that activities they did when they were first injured may need to modify as they age. For example, the skin is less forgiving for sliding board transfers and accidentally bumping the wheel with transfers. The best medicine for pressure sores is prevention. Healing can take a long time. Early treatment of sores is very helpful. Persons should be diligent about checking there skin. Use of a mirror to check your skin and or having a caregiver check your skin on a regular basis is key. The surface of your skin may not look so bad but there can be significant damage occurring below the surface. Correct seating and correct shoes help prevent sores in these two key areas. Once a sore is acquired it is important to stay off of it 24 hours a day. Nutrition is important and having healthy meals with three proteins a day is important for healing. Hydration is also important for healing. Once a sore gets down to the muscle and or bone the body cannot regenerate the muscle, fat or bone. Changing habits that led to the sore is important as well as keeping yourself in shape.

7) What are the limits of confidentiality?

The unit of care is the Treatment team. Confidentiality is kept at the team level. Nothing is disclosed outside the VA and this is part of HIPAA.

There are four exceptions to provider patient confidentiality;

- a) Suicide
- b) Veteran makes credible threat to identifiable individual
- c) Child abuse
- d) Elder Abuse

8) What are the differences with the Inpatient and Outpatient Spinal Cord Injured unit programs?

The programs are designed to try to keep the traveling distance down. That is if you live locally the VA tries to get needs taken care of on an outpatient visit. The VA Palo Alto serves as a hub for annual evaluations. Inpatient stays are used for annual evaluations to try to get care needs taken care of efficiently for people who travel from afar. The outpatient program has the same type of interdisciplinary team as inpatients. There are some specialty clinics like the Upper Extremity Clinic and Wound clinic that are not done as inpatient clinics.

9) Why is my blood drawn and what is it used for?

Blood is drawn as part of the annual evaluation for basic evaluation including blood counts, cholesterol and diabetes risks to name a few. Serial blood draws are done for tracking medical conditions, some examples of these include, infections, inflammation, wound healing (serum protein levels). Individuals with acute medical needs usually need more blood draws to evaluate their condition and treatments that are being done.

10) What are the different types of Multiple Sclerosis and what can I expect in the future? How does Multiple Sclerosis affect the Brain and Nervous System?

The Body attacks the myelin which is the covering around the nerves. The cause of MS is not known. The results of MS are weakness, decreased coordination, visual changes, and bowel and bladder changes. There are four categories of MS that are used to help distinguish the prognosis and the drug choices for treatment. The four categories include; Chronic, Relapsing, Primary progressive and Progressive.

11) Who plans our menus and how can they be more appetizing and satisfying?

Meals are planned at Menlo Park by Lurese LeVoir 52-27372. Also ask to speak with your in-house dieticians.

12) What are the various adaptive sports programs for Spinal Cord Injured patients locally and nationally? Where can I train to be a para-athlete?

Get in touch with your recreational therapist for assistance in getting started.

There are numerous centers a wide range of activities

- Camden community center in San Jose-community recreation facility that has an accessible gym (weightlifting and other equipment) as well as a wheelchair basketball program for youth and adults.
- Timpany Center in Santa Clara (just behind SCVMC) therapy pool and accessible weight room.
- BORP-Adaptive sports program in Berkeley (kayaking, cycling, wheelchair basketball, wheelchair tennis, and other clinics throughout the year
- Access leisure-Sacramento provides adaptive sport opportunity through periodic clinics and events weekly/monthly.
- Riekes Center-Adapted archery, laser rifle, sit volley ball, quad rugby, strength and conditioning, Tai-Chi, and Biathlon training.
- Disabled Sports USA-National organization that provides adaptive sports programs for people with disabilities across the U.S. year round (downhill skiing, water skiing, outdoor adventures, kayaking, cycling).
- Winter Sports Clinic-March every year in Snowmass, CO primarily snow skiing (mono or bi-ski). Also has cross country skiing, community outings, gondola rides, snowmobiling, scuba diving, rock climbing, social events, curling, and more.
- National Wheelchair Games is an annual competition where veterans can compete in up to 5 events of choice. Some of the events include: Wheelchair basketball, quad rugby, power soccer, softball, wheelchair tennis, table tennis, archery, trap shooting, air rifle, bocce ball, billiards, power lifting, hand cycling, bowling, swimming, and slalom (intense obstacle course).
- Funding opportunities: PVA point system, Challenged Athletes Foundation Grant (Operation Rebound), Wounded Warrior