TIPS

ENJOY THE HOLIDAYS

In your social life as pALS you have to enjoy the New Year celebrations.

As the year comes to an end you would like as PALS appear around the Christmas table or on New Year's party in festive mood. And also your family and friends are glad to talk in a relaxed atmosphere and hear you laugh. Those are the unique delightful moments that you simply may not miss! On those memories you can pull yourself up for a long time. To prepare yourself we've gathered some tips that will that will improve the revelry.

A general tip applies to all pALS: try in advance to find out if the place you are invited is accessible for you. Are there steps that constitute an impossible hurdle, will you be able to get over thresholds or level differences in the house of your hosts? If the necessary favorable conditions are not fulfilled then suggest to organize the party at your home.

Organizing means of course a huge mountain of extra work. But dare to count on the solidarity of your family and friends. You'll notice that your guests like to make some effort to succeed the party. Ask them to do precooking performance and each prepare a part of the feast and bring it along. In extreme there's also the possibility to call a catering company. But never let anything

prevent you to fill that party table.

For pALS who look up to a feast because they are using a PEG probe, we also have a few tips. Of course you will join

only limited the festive table, but nothing prevents you to

taste delicious. Remember that it's also possible to inject wine, beer or any other party drink through your feeding tube. That drink you can taste by gently burping the liquid. This way you can enjoy the cozy festive atmosphere and no one will begrudge you this pleasure. Make sure you've a BOB if needed to drive home!

And when on New Year's Eve around midnight the big toast on the new year is held with filled glass, you can also participate. Ask your partner to dip his or her finger in the champagne and then put it in your mouth, then there's nothing lost of moment 's flavor. When you can focus on that, it will be as fine as lifting the glass yourself. You are there and being part of the fun, you can enjoy the coming year without thinking of all the difficulties that will come.

LIFE WITH A PEG PROBE: A STEP FORWARD IN THE FIGHT AGAINST ALS.

In your social life as PALS you have to enjoy the New Year celebrations.

pALS using a PEG probe as a tool for their food quickly discover the great benefits. The feed pipe is for him or her a necessary tool that makes life with ALS easier to cope with. It is indeed the comfortable and safe way to get the necessary energy from food: you lose no more energy because of chewing problems and you won't needlessly swallowed. Food is no longer a torment and you can even enjoy the taste what you liked so much enjoy by putting it in your mouth like a taste explosion and possibly spit out again. You can indeed do it with an aperitif or a sip of wine

A PEG probe which makes your life less complicated because the care gets easier. You take a meal of total liquid diet and then you can still join the family meal and you can get a small bite to eat or sip a drink. That probe meal you can take in advance in peace and discretion and get the energy you need to extra enjoy the Family. Also the

maintenance of your food pipe is easy, a simple routine which takes little time. The only practical arrangement that you take with your caregivers that you wear the feeding tube securely on your body.

As pALS you'll need to turn that proverbial button from the moment you start eating through a tube. Focus fully on to the benefits: you

will be more energetic and less stressed! You're more energetic because you eat enough, and meanwhile you'll get all the vitamins, proteins and so in. You're less stressed because you don't any longer have to look with anxiety at the difficult and sometimes painful sustainable food that takes so long because chewing is too difficult.

And fear of choking that takes nearly the form of suffocation is also behind us. You're with the PEG probe your ALS one step ahead

because you've taken a hurdle successfully.

The ALS team



NUTRITION TIPS FOR PEGS

ALS patients who use a feeding tube (PEG) questioning which food is now allowed with the probe. This is mainly because a lot of patients still give preference to their own healthy food instead of sold canned food. Some patients have never eaten canned food before. There are also patients who ask if they can use vegetarian or vegan food.

By using a blender, a device to puree the food, there is normally no problem to prepare your own food. Making your own probe food is usually much cheaper than the special sales formulas. And most people still love the aroma of their own homemade food. Another additional advantage, one knows exactly what ingredients and nutrients used in the own prepared food. Of course preparing the food yourself takes more time then opening a can, and this effort can be very tiring for some people, especially if one wants to do this for all meals.

Almost all food which can be used in the PEG you find at the grocer. Ingredients like carrots, green beans, vegetable oil, apple muslin and other nutritious foods can be used. There are also recipes, where they use baby food, this to shorten the time of the mixing.

When you prepare your own food for the PEG, make sure that the food is good pureed so that the tube can't get obstructed. It is very important to avoid meat and fish products, as well as some vitamin supplements that contain a high fat content, such as vitamin E, Omega 3 and other fats and oil products. If you like the taste, you

can also pulverize nuts and mix with the food, because nuts are high in fiber and have a high value nutrients. Make sure you rinse thoroughly the probe after use.

To puree the food there is a whole variety of devices from a juicer till a real food processor. Some of these devices leave unfortunately fibers of vegetable substances behind, but soluble fibers can be added in the form of products such as Metamucil[®].

Some patients want to enjoy a "cocktail hour". It's fine for them to enjoy wine, beer and other alcoholic drinks diluted through the PEG. These people enjoy so much of this glass, that they subsequently feel more sociable and relaxed.

When you are traveling and you like to spend less time preparing your food yourself, you better go for vegetable protein formulas found in some products. Or you can take Instant Breakfast with milk if you like this.

But certainly discuss first and foremost your homemade diet with your doctor or - better yet - with a nutritionist who works with the ALS Liga or the hospital. It is very important in order to get a balanced diet, which contains the necessary quantity of important nutrients.

Finally, we would also like to refer to the pdf brochure "Nutrition with ALS" on the website. In this brochure you can find a lot more information about healthy eating in general, and tube feeding.

