NEW ZEALAND POLIO CONFERENCE SEPT 2008 - "JEGA" FROM WA IS KEYNOTE SPEAKER

To Tessa,
Thank you for introducing us to JEGA!! What a great conference we had in NZ. I believe that that was the best *"Hands On"'* experience that our members have ever had. With just 54 at the Friday and around 36 on the Saturday it was really good value for those who took time to attend. Such a knowledgeable lady to boot. **Ray Wilson, President of the NZ Post Polio Society**.

DVDs of the NZ Conference are **available** to order over the Internet from **www.faithnet.co.nz** or by writing to **Faithnet PO Box 12357 Hamilton NZ**. Set of 4 discs for **NZ$80 plus postage**. There are 3 discs with Jega, one describing our LED clinic, one showing practical polio assessments on 2 volunteer patients and one demonstrating pool exercises with 3 polio volunteers. The other disc has a talk by each of the other speakers, Dr Jurian de Groot on PPS and David Guest on equipment. This set of DVDs is well worth having.

Jega spoke along similar lines at our recent AGM. The following is taken from both talks. Tessa Jupp RN

"Jega"

Jega has been the *"prime mover"* of the Late Effects of Disability Clinic (LEDC) at RPH Shenton Park since its inception in 2000. She is ably assisted by other senior physios in their particular fields of expertise at RPH Rehab. Dr Dade Fletcher, Rehab Physician, heads the LED clinic. To date 340 patients have been assessed through LEDC and two thirds of these are polio survivors. 89 patients have undergone reviews, usually more than once.

Preventing falls
Jega is really concerned about the potential for falling and says - *"Pain can make you fall. **It only takes one fall to break a bone.** Polios need to concentrate on walking and it only takes a minor distraction to cause a fall."*

Over the years, Jega has realised that staff should never try to change the walking styles that each polio person has developed. She says *"You are more likely to fall if you are not using these trick movements which are now programmed into your brains."* Jega is aiming to get us back to where we were 3-5 years ago so would like to see people sooner, before they run into too many problems so that she knows how good you were and how you managed before.

Preparing for Surgery
Tell Jega as soon as you are put on the waiting list for surgery. She would like to be involved with your physio/OT/surgical team preparation meetings months beforehand so that plans are in place for when you leave hospital.

An example Jega used is where she was called in for someone whose legs were weak or paralysed and needed to use a goose-neck to move her position in bed. The ward staff would not allow her to use the goose-neck saying they are old-fashioned and could cause shoulder injury. However Jega was able to explain that it was necessary for this polio person, as she had managed this way for a long time. And so the problem was happily resolved.

Plans also need to be made for how you shower, move around in the house, use the toilet, get the shopping done etc once you go home. It is hospital policy everywhere these days to get the patient out of hospital in a very few days, but for polios, staff need to know that it will take longer to recover for polios and going home too soon could result in a return to hospital with a fracture from a fall that could have been prevented by taking time to make sure your balance is stable.

Other problems that may occur are that the staff may expect you to be able to hop on the other leg post surgery, but this may not be an option for you if that is your weaker polio leg.

Staff may also try to alleviate stiffness, not realising this is being used to compensate for weakness and to maintain balance. Trying to change this is more likely to lead to falls.

Shoes and Calipers

Some people do need soft shoes and soles to enable them to grip the floor with their toes to maintain their balance. Others may need the support of firm ankle leather to maintain foot alignment and ankle stability. It depends on the individual. It is also important to have shoes the correct size for each foot as you are more likely to fall over the extra length on the shorter foot if you don't get 2 pairs of shoes to get a fit.

Off-the-shelf orthotics don't work for polios as they are made for normal musculature not for the muscle wastage common in polios. The wrong caliper, orthosis or shoes can cause loss of sensation in the leg or foot, pins and needles and greater likelihood of a fall. They need to be specially made and fitted to polio legs. Shoes and boots that are too heavy will make the foot and leg tired and weaker too.

When being fitted for new calipers and orthosis, you should have a new muscle assessment by a physio to see if changes are needed before the new caliper is made. The aid needs to be fitted to the person not the person to the aid. Don't try to change the person. It won't work.

Jega encourages us to speak up for ourselves. Don't let others dictate to you what you need. You know yourself better than anyone else.

Aids and Equipment

Jega says that polio people should consider the use of aids sooner rather than later and admits there is a general reluctance to do this. She says that walking sticks should only be used for confidence when walking. If we are using a walking stick or frame to lean on or to maintain our balance, then we are too weak to use it. A walking stick will slow us down. It will create shoulder problems from using it to take our weight on it. So we need to advance to the better security of an elbow crutch (or two), a walking frame with a seat rather than a Zimmer frame or to a wheelchair or scooter.

If our arms are getting weaker then we should use an electric chair or a scooter - they are getting cheaper these days. But the wheelchair needs to be fitted to the person too. The base and length of the seat need to be right as do the height of footrests and armrests. And Jega is now arguing the need for both manual and powered chairs, and spare calipers and shoes to use when our others are being repaired.

Exercise

Jega has found that polio muscles have a better holding capacity than the ability to move. This is different to the frail and aged who can't hold or maintain position. When polios are moving, they can't change direction. They must stop to change pathway direction, otherwise they are likely to fall.

Muscle overuse causes weakness and rapid fatigue of muscles. If at the end of any activity we feel tired - we have done too much.

Other overuse signs are

- Exhausted next day
- Muscle or joint aches
- A creepy crawly sensation
- Jumping legs
- Legs that feel like "jelly" or like "lead boots"

Sometimes just daily living tasks can be too much exercise. Spread tasks out over the day or over several days. Do less at a time. Take frequent rest breaks. Do something you enjoy.

Muscle Training

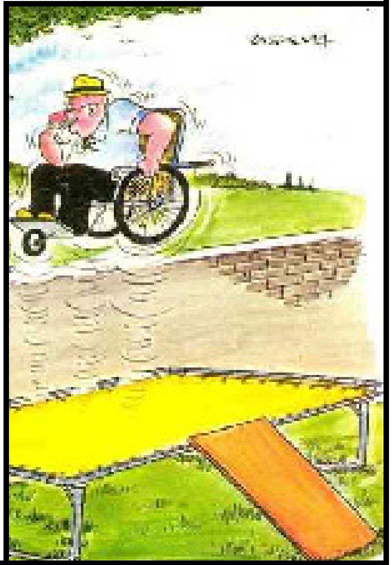
Everyone's capacity is different and exercises need to be tailored to individual muscle strengths and weaknesses.

General rule is

- find the maximum that you can do in one go then work at 50% of that if some weakness and at 70% if no weakness in that muscle
- Rest for half the time it takes to exercise
- Always stop before you feel tired
- Train with caution, it is easy to cause a strain
- Increase by small amounts every 2-3 days
- If feeling unwell reduce amount of exercise
- Don't exercise if you are tired

Group Sessions

Polios don't do well exercising in groups. They feel obliged to keep up so as not to hold the others back. Polio people do better with individual programs, working at their own pace. This can be done in small groups but without the competition element.



I finally found an exercise I like!