

## “Yesterday, Today and Tomorrow”

Elizabeth Martin and Thistledome Team

Twelve years experience of Independent Living and the challenges faced when paralysed below the neck.

### MY AIM

- to enjoy my life as much as possible for as long as possible
- to avoid preventable complications
- to retain control of my choices and decisions.
- to be aware of the ‘cost / benefit’ implications of care choices.

### YESTERDAY

My initial challenges were NOT those associated with leaving a hospital high dependency unit but experiences of finding that my physical disability was considered to be associated with a mental disability also and I was offered ‘advice’ by those without relevant experience. Some felt that with such a severe disability I would be better to remain in hospital. I referred my dilemma to a Clinical Ethics meeting at Imperial College with the Title: Clinical and Ethical Issues in High Spinal Cord Injuries.

During my first year at home an agency provided Care Attendants for my needs. As I gained confidence in my safe care I decided to try and develop this under my own control - prior to my accident I had been a controller in the Strathclyde Fire Brigade. Discussions of the Disability Rights Commission and of the Public Sector Duty convinced me to go ahead and learn to be my own Care Manager. This presented a further challenging situation - ‘who was I to make decisions about my own care which did / may contradict those of the ‘experts?’. How was a professional to take responsibility if I was going to give instructions?

To maintain my safe care, education and assessments needed to be developed. I applied to do the O.U. Certificate Course in Health and Social Care. Excellent educational backup help supported my introduction to computers and voice recognition expertise. Passing the exam was a boost to my confidence - ‘I had passed on my own merit uninfluenced by my disability’. One of my other PA's has completed the course and two others have completed the Coatbridge Courses - ‘Care Principles and Practice’ and ‘Moving and Handling’. I have laminated photographs for reference on pressure sore prevention and physiotherapy exercises.

Over my twelve years at home, I have spent just three days in hospital for adjustment of my pain medication; I have avoided pressure sores and major infections. bacteriological specimens go to Stirling Royal Infirmary and antibiotics are prescribed by my GP practice.

### TODAY

Networking involves a personal effort to discuss and learn from the experience of others with similar needs. I have also identified an ‘advisory group’ with whom I can consult for expert advice. I was elected a Trustee to the Spinal Injuries Association and am now completing my sixth year in office. The meetings are held at their headquarters in Milton Keynes. Thus I am an ‘experienced wheelchair / rail user’. The International Ventilator Users Network (IVUN) and have been invited to join the IVUN Consumer Advisory Group. I keep up to date in Scotland with SPEAN and SIS. I communicate with QENSIU but keep them in reserve! I am in my fourth year of awaiting a replacement Power chair suitable for my needs.

Over the last two years I have renewed contact with past colleagues in the Strathclyde Fire Brigade. I attend the Forth Valley Health Board and PPF Meetings. The PPF has been excellent at introducing and integrating me into the local CHP groups. I asked at a dental meeting whether ‘it was possible for my carers to be taught “how to clean my teeth”’. They accepted this challenge and the outcome for my teeth has been excellent. ‘Dial a Journey’ also provides an excellent alternative to individual transport arrangements. When will the UK introduce equality of access to public transport for the disabled wheelchair users? (It exists in Lyon).

### TOMORROW

- (a) I hope that outcomes of decisions and outcomes of care will be evidence based and become an essential part of evaluation and comparison with other units.
- (b) That focus on user choice; safety; effectiveness to care and direct access to informed support, backed up monitoring, telemedicine and collaboration will become routine.
- (c) Training and assessment courses will be developed, evaluated and based on a clear understanding of the problems faced by the user. Could this include the SVQ qualifications and lead onto a ‘national’ qualification?
- (d) QIS information e-news for October proposes – “Developing / delivering the Aims of Tomorrow”. I hope that these agree with mine.



“Many thanks to all those who have been involved in my successful time at home and in contributing to this poster.”



Experience of routine travel for disabled on public transport in France



Eurostar



Liz in shopping centre in Lyon



Firebrigade reunion



At the community dentist



Physio exercising



Snow and carer arriving by tractor

