

# Psychological Adjustment After Paralysis

**Victoria Holton**

# At the time of my accident, I was:



- 31 years old

- Single

Degree in three dimensional design then moved into New Product Development.

- A Marketing Account Development Manager

- A runner, skydiver, mountain biker and indoor climber

Running - my pre-accident stress relief activity.

# My Story

- In 2002, I had a fast landing whilst skydiving in Spain. I touched down feet-first and fell over, breaking C5
  - The moment I did it, I felt sure I was paralysed.
- I was taken to Seville Hospital and went into surgery within 12 hours to repair C5, stabilising it with some bone from my hip and titanium.
- I had a tracheotomy and was reliant upon a ventilator within 4 days Pneumonia
- I returned to the UK after 19 days
- I spent 18 months in the Salisbury Spinal Treatment Centre
  - Approaching the sixth anniversary of my accident, I have not yet used anti-depressants

# THREE PHASES

- Difficult presentation to write. No linear progression. A yo-yo of emotions. I've looked at it by time, splitting it into three phases:
- **Acute/Rehab**
  - Time spent as an inpatient
    - A time where, no matter how bad things are, you're going through it with lots of others. That makes a big difference.
- **Life outside hospital**
  - Initial period after discharge
- **Longer term**
  - The rest of your life A daunting prospect.

# ACUTE PHASE

## The First Nineteen Days in Spain

Three key factors to coping:

- **Ignorance**

Spanish doctors decided not to tell me I was paralysed. I was asking questions but received evasive answers. Even though I initially thought I'd paralysed myself, doubt crept in because no-one had confirmed it.

- **Blurred thinking due to morphine**

- **Blind belief in the medical profession**

# ACUTE & REHAB PHASES

## Coping Mechanisms

- Came back to the UK and Dr Soopramanien told me that I was paralysed and it was likely to be permanent.
- **Denial**
  - This can't have happened to me
  - I'll prove the doctors wrong
    - Families used denial to cope too.
- **The Cure**
  - OK, maybe I am paralysed but it won't be forever
  - **Christopher Reeve** – High profile, very vocal about walking before his 50<sup>th</sup> birthday.
    - Friends used to bring any newspaper articles to the hospital about cures – rats moving paws etc. Quite sure a cure was on the horizon.
    - Later in rehab, we used to laugh quietly at newer patients who would get off bed-rest and come to the dining room to talk about the cure, just like we had.

# ACUTE & REHAB PHASES

## Coping Mechanisms

- **Hard Work and Determination**
  - If I work hard, I'll regain the use of as much of my body as possible
  - A positive focus
  
- **One Day at a Time**
  - Not thinking too far ahead
    - Difficult to avoid making plans for the future. I registered with West Wilts wheelchair services (where my parents lived), Brighton & Hove social services (I was working in Sussex at the time of my accident) and then moved to Dorset!
  - Only dealing with issues when I was ready
    - I avoided art classes at the spinal unit for 6 months, unable to face the frustrations and disappointment of painting with paralysed hands.

# ACUTE & REHAB PHASES

## Coping Mechanisms

- **Hope Through Knowledge**
  - Meeting others with similar injuries who have re-established fulfilling lives
- **Camaraderie** NATURAL PEER SUPPORT-MASSIVE HELP. Lucky to be in Unit with a bunch of characters!
  - Being surrounded by other recently paralysed people Constant therapy. We were always talking about what had happened to us.
- **Mourning – Loss of my old life and of future opportunities** Stupid things like I wouldn't be able to wear a beautiful long coat that I'd just bought as well as bigger issues like the fact that I felt sure I'd blown my chances of ever having children.



# ACUTE & REHAB PHASES

## Coping Mechanisms



- **Black Humour**
  - **Bi-ped bastards** We were very envious of anyone who could walk.
  - **Jobs for tetras** – Paperweights! Door wedges!
  - **Lack of suicide options for tetras**
    - It seemed that, given forewarning of our imminent accidents, we all felt that death would have been the easy option.
  - **Paras v's tetras**
    - Even though our bodies and lives were in a state of devastation, we laughed so much.

(Cartoon by American tetraplegic John Callahan)

# ACUTE & REHAB PHASES

## Coping Mechanisms

- **Support**

- Family, friends, work colleagues

- Hundreds of e-mails, cards, flowers, visitors. Bad news travels far and fast.

- Family – my parents thought I was coping so well so they had to cope too so that they didn't let me down. I was thinking they were coping well and I didn't want to let them down. We were all being strong for each other.

- Strangers Christopher Reeve wrote me a letter.

- **Release**

- Tears, anger, exercise, alcohol

- Minor explosions around the Spinal Unit. Patients shouting to vent anger. Me in tears to release my despair.

- **Distraction**

- Books, movies, sleep

- ANYTHING to distract you from the awful reality.

# ACUTE & REHAB PHASES

## Other Issues

- **Loss of identity and self confidence** Felt like a giant baby-initially unable to feed myself, doubly incontinent. Awful first Christmas being cared for by my parents.
  - Physical changes-avoiding mirrors. Awful trachy scar. Size 8/10 body slowly morphed into a toneless blob.
  - Clothes – even the type of underwear I wore had to change.
- **Loss of control over basic decisions** What/when to eat, get up and go to bed.
- **Lack of dignity** Bowel care on the bed with 3 other patients in the room doing the same thing. NO DIGNITY.
- **No privacy**
- **Frustration**
- **Patience and tolerance**
- **Boredom**
- **Guilt** Becoming a burden to my parents at a time in life when I should be thinking about looking after them.
- **Worry over future – work, home** The future – a terrifying concept.

# AFTER THE SPINAL TREATMENT CENTRE

## Initial phase Keeping busy setting up my new life. Getting basic routine and facilities in place.

- **Fear** Twofold – one – leaving so much knowledge and expertise behind. Two – had to make a life for myself now. I knew I was failing if I found myself watching daytime TV.
- **Setting up a new environment** so that I could be as independent as possible.
- **Establishing a routine**
- **Regaining some control and choices** – What to eat, when to get up etc.
- **Getting used to PA's 24 hours a day** An early PA I had was a horror! We arranged the kitchen, she re-arranged it! She talked for me, not allowing me to answer questions. She was bossy, overbearing and judgmental. I called a friend who had been paralysed 20+ yrs and he said "Get rid of her!"
- **Functioning in everyday life at a much slower pace** One thing a day to start with. To try to do more was stressful.
- **Minimising expectations of life** Trying to be happy with almost nothing then everything extra was a pleasant bonus.
- **Frustration** A continual problem.

# Frustrations

...anything to do with care funding a fight to get enough to buy good quality care ...bed-rest...having to tell the hundredth person how you'd like your drink made and that's just one tiny aspect of everyday life that you need to verbally communicate ...taking 2 to 4+ hours to get up everyday when you really just want to spring out of bed and get on with life...being patted on the head...asking someone a question and watching them answer your PA...being mothered, judged or told how I should live my life by PA's...eating lukewarm food...being dressed badly why do some PA's think you'd want to go out with one trouser leg rucked up ...almost constant financial assessments...never being truly alone...rarely having hair styled the way you'd do it yourself...being further restricted by a PA's shortcomings terrible drivers, don't always possess a good command of the english language ...not being able to go for a long run to get rid of my frustrations... this list is endless

# AFTER THE SPINAL TREATMENT CENTRE

## End of the initial phase

- **Sinking Feeling** – I'd run out of things to do to keep myself busy and started waking up wondering what on earth I was going to do with myself all day.
- **Making the best of it** one life, two choices – to be happy or sad. I genuinely wanted to be happy. Moaning, depressed people are boring.
- **Dream of a cure** Still looking for a positive escape from paralysis when I was struggling to cope.
- **Peer support** I initially shared a house with another tetraplegic. Still in contact with lots of other fellow patients.
- **Letting go of the past** A sure-fire way to depress yourself is to compare your old life with the new.
- **Avoiding boredom and isolation**
- **Wanting to be 'useful' but not ready** didn't want to take too much on and fail.
- **Yo-yo-ing emotions from one moment to the next**

# AFTER THE SPINAL TREATMENT CENTRE Distraction, usefulness, sense of achievement

These days I keep busy helping the Southern Spinal Injuries Trust and the BioMed Centre



BioMed Health Technology Co-operative

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## Newsletter

### Open Day

The BioMed Health Technology Co-operative (HTC) celebrated its third anniversary by inviting guests from its stakeholder communities to an Open Day on 14th February 2008. The Chairman of the Bristol Urological Institute (BUI) trustees welcomed everyone and a series of short presentations followed, looking at the value of the BioMed Centre from different perspectives.

We were privileged to hear from Dr Bill Mason-Hewarth and Miss Jill Dhall from the Department of Health (DH) who expressed their thanks to everyone involved for their drive and enthusiasm over the past three years. Central to the original DH decision to provide funding was the aim of creating an environment where NHS needs can be better identified and whose effective partnerships with academics and industry can be brought about to work on developing solutions. Dr Mason-Hewarth commented "It is particularly encouraging that we are now starting to see a range of benefits from this type of endeavour and learning from the BioMed Centre over the course of the past three years is now providing valuable input into the new National Institute for Health Research (NIHR) 'investment for innovation' programme."

Mr James Lins, Sales & Marketing Director of Medplus Ltd, described the BioMed HTC as an invaluable independent resource to industry.

He was keen to emphasize "the crucial role that the BioMed team carry out when evaluating new product ideas, utilising their vast knowledge and experience to direct projects to the most effective conclusion. The BioMed Centre also offers state of the art facilities and the expertise to test new products in an era when an increasing amount of evidence is rightly required by regulatory bodies before a new product can be marketed."

From my point of view, the BioMed HTC offers hope. Having sustained a spinal injury five years ago, it has taken a huge amount of effort to come to terms with being a wheelchair bound paraplegic. Living with an inverting catheter and leg bag has taken an even greater effort to accept. It is disappointing that there have been such huge advances in most areas of medicine, yet treatments for urinary incontinence almost seem to have stood still. The most commonly used catheter today was designed in 1907, back in the days when a black and white television was still a very rare sight. With its well documented drawbacks, life with a Foley catheter can easily turn into a series of embarrassing soaks and painful infections. You'll understand why I was so heartened to meet the team at the BioMed Centre.

Vicky Hutton

**Contents**

- BioMed HTC Open Day
- Euge in your bladder
- Dirk, Dirk, Dirk!
- Bladder catheterisation
- The Innovation pathway

**BioMed News**

- Evidence, experience and expectations for the future
- New Faces

**Award for Professor Roger Fenley**

Professor Roger Fenley received a light-hearted expression of thanks from the BioMed HTC for his enormous contribution to the Partnership. The quirky award, a miniature model of Roger himself complete with Foley catheter in hand, was presented by Ms Margot Cooper, President of Limbs and Things. Ms Cooper's company had kindly crafted the model.

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Association for  
Continence Advice

Annual Conference  
& Exhibition 2008

Conference Information &  
Delegate Application Form

- Delegate costs reduced by over 35%
- Glasgow - "Scotland with Style" and a venue not to be missed
- A fascinating programme
- Partnership with the BioMed Centre Bristol

GLASGOW  
Scottish Exhibition and Conference Centre (SECC)  
13-14 May 2008

Professionals United in Continence Care

# AFTER THE SPINAL TREATMENT CENTRE

## Approaching six years post-injury

- Every single day is still a challenge
- Time, acceptance, adjustment Helps to some degree.
- Move forward Find new challenges. Avoid comparisons with pre-accident life.
- Regaining self confidence
- Achieving personal goals
- So much of life relies on others-lack of control
- Fear of the future It just takes one budget cut and my care could be scaled back, compromising my quality of life. One little red mark on my skin can mean days/weeks of bed-rest.
- When in despair – hope for a partial cure edging slowly towards realism! I've given up hope on a complete cure, nowadays dreaming for just enough to live independently.