**Abigail Methley – Coping with TM Emotionally, Helping family and friends to help you**

Everything should be in context to you. Do not compare yourselves to others as everyone else is different.

Problems with TM

There are 3 main problems with TM and these are as frustrating to Health Professionals as they are to the people living with TM and their families.

1. Unpredictable - no one knows what the future holds for you
2. Knowledge – no one can explain to you why this has happened “Why me?”
3. Adjust – you have to adjust to your new life but it is very difficult to accept what has happened

Emotions associated with TM (spinal Cord Injury)

1. Depression 48-50% of people get depressed so this is a common thing, but not inevitable- it also means that half of people will not experience depression at a clinically significant level.
2. Anger – not just from the person living with TM but also their families – it affects many lives and often is very difficult to cope with.
3. Anxiety – not knowing what is coming next
4. Grief – for the life you had and the things you thought you had (the future) – planning to go on holiday in 5 years cannot now do that
5. Denial – cannot face up to what you are now living with
6. Quality of life – where did you expect to be – look at what’s important for you to achieve.

Your condition can take over the way you see yourself you can start to become a patient not a person, or you start to see yourself as the condition. You need to find a way of living with TM and still being yourself

NMO Study on Quality of life

Patients living with NMO were asked what was important to them in their life. These are the most common answers:

1. To have a purpose every day
2. Expectations – looking around at what your friends and family have. Concentrate on your own expectations not on what others are doing.
3. Independence v Support – everyone will try and help you be aware that they are supporting you not taking away your independence. Make sure you are not sheltered.
4. Physical symptoms that stop you doing what you want such as pain, fatigue, incontinence etc. (Check this- correct!)

How to improve your quality of life

1. Get as much information as possible – find out if there are any local services that can help you, Use the internet but be cautious of what you read. You need to be in control of the information you chose to digest. Health care professionals will always help where they can and if they can’t they will often point you in the right direction. You need to gain control of the information you receive.
2. Peer Support – People living with TM are lucky that they have the expertise of others through the TMS and their facebook pages. Some people may be scared of peer support as they will see what others are like further down the line. People should understand that everyone is different. There are also online forums but sometimes these can have a negative twist on things. You need to know what support you need at what time and the support you need may change over time. For example you may want lots of support at the beginning and less as you learn to adapt to TM.
3. Coping strategies. Set aside an hour a day for “worry time”; the rest of your day will be worry free as you know you will be dealing with it later. Make time to write a journal as it helps to make sense of your feelings and see it from different perspectives, this may then make it easier to share these feelings with others. Often with TM you lose contact with friends because it is difficult to socialise with them; find time to pick up a phone and chat.

Ensure you set goals. If you don’t have goals you have nothing to work towards. Make them SMART goals (Specific, Measurable, Achieveable, Relevant, Timebound).

Be proactive with your well being especially your mental health. Use services around you to help you efficiently.

1. Professional Support – Find ways to overcome difficulties, GP can point you to help.

Ensure you are in control of how you are living with the condition and that it is not ruling your life.

Finally, remember the positive things you have already achieved, and set goals for the positive things you will achieve in the future.