

Oxfordshire MNDA Newsletter Winter 2019

Pick a day. Any day. *Every* day is a special occasion; it cannot be repeated; it will never come again. So, six o'clock is Gin o'clock! Well it is for Susan and me; we always toast the day. However difficult or depressing it may have been, we try to find something to give thanks for; children and grandchildren, friendships, nature, good news, good weather! anything.

It began when Susan found she was losing the spring in her right heel. Eventually it was agreed that she had an unspecified neurological problem; that was 31 years ago. After another five years of investigations, tests and drugs, she was finally given a label, Primary Lateral Sclerosis (PLS), a form of Motor Neurone Disease (MND). Er, so what's the diagnosis? The danger is, being human, we automatically fear the unknown and look at the worst-case scenario. Well Susan is now wheelchair dependent, and voice-challenged. But she still '*has an image to maintain*', and her indomitable spirit is an example to everyone of how to face up to life's unfairness. And while we fret and worry, life is in danger of slipping by; and *none* of us knows how long we have left. But ours is a team effort.

So we decided a long time ago, that life for all of us, is too short and too precious; live it, don't waste it. I'm not pretending it's easy, it's most certainly not. There are periods of depression and panic attacks, and lifestyles inevitably change. But we are all so well supported, if we take advantage of what's offered; the Neuro team at the JR, the facilities afforded by Social Services' many therapists, and of course the wonderful support of the MND Association, both nationally and locally. Make sure you are signed up to Oxfordshire Carers, and see what marvellous support they too have to offer. (www.carersoxfordshire.org.uk)

Never get to the stage when you say, '*I wish I had done ...*' or '*If only I had my time over ...*' You can't. That's gone. Get over it, and get on with life, push yourself, to meet people, follow your hobbies or find a new one; record your voice now, write your memories for your children and grandchildren. Susan (75) and I (80) have finally given up flying to exotic parts, but it has opened up new opportunities to visit places in our own Country, which we loved in the past, or are still waiting to be discovered. Facilities for people with mobility problems are vastly improved in hotels and public places. Surf the internet, you'll be amazed what's on offer.

Howard Brayton

(Susan's husband, lover, best friend, and carer)

