



MARIA CASE STUDY

Specialist knowledge & intervention
– Tania Burge, Bristol

AT A GLANCE CHALLENGES

- Rapidly progressing MS
- No movement in her body
- Poor speech & swallowing resulting in frequent chest infections & hospital admission
- Painful spasticity
- Unwilling to discuss end-of-life care

AMSC INPUT

- Trusted relationship with AMSC
- Willingness to have PEG and catheter fitted
- Has put an advanced care plan in place

"Having an MS Champion in my life has helped and assisted me tremendously. I can discuss any issue with her, and she forwards it to the relevant person and my issue is dealt with efficiently and effectively. Having an MS Champion supporting me floods me with confidence to live my life – not just survive. Not all super heroes wear capes!" – Maria

SITUATION

Maria is 46 years old and was diagnosed with MS in 2002. Her MS has progressed rapidly, leaving her with no movement in her body and poor speech and swallowing. Maria lives alone in a fully adapted house, with twenty-two hours of care a day.

BACKGROUND

- Inability to swallow or cough effectively causes food and fluid entering her lungs (aspiration), resulting in repeated admissions with chest infections (70 days in hospital over the past five years).
- Extreme tightness and muscle spasms, resulting in deformity, pain, and pressure ulcers.
- Neuropathic pain caused by MS damage to the sensory nerves, resulting in very uncomfortable sensations, such as intense burning or sharp, stabbing pain.
- Unwilling to discuss palliative care as Maria believed this would give the message that she didn't want to live. She perceived interventions like a feeding tube (PEG) to eat and drink as a 'downward step', even though it could reduce aspiration and potentially improve quality of life.

AMSC INPUT AND RECOMMENDATIONS

- After initially establishing trust between the AMSC and Maria, the AMSC convinced Maria to have a feeding tube and a catheter fitted to improve her quality of life and sleep.
- The AMSC supported Maria's GP to provide medications that will ease spasticity without causing muscle weakness or fatigue.
- Their trusting relationship enables them to discuss end-of-life care. Maria has now made an advanced directive, with AMSC Tania acting as her advocate at future meetings.

OUTCOMES

- Maria is now at the centre of her own care, working together with her AMSC as joint experts in her MS.
- Maria's pain & spasticity drugs are properly monitored to minimise unwanted side effects.
- Introduction of PEG improved nutrition and hydration and reduced risk of respiratory infection and emergency admissions.
- Improved sleep, thanks to fitting of catheter.
- Maria now feels able to discuss end of life, and has made an advanced directive.