Complex Cancer & Palliative Care Allied Health Professionals

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Macmillan Complex Cancer and Specialist Palliative Care Allied Health Professionals (AHP) team.

(For the purpose of the case study the above will be referred to as the 'Macmillan AHP Team')

John and Mary.

John was a 62 year old local successful business man and lived with his wife Mary; they enjoyed life, had a busy social calendar and had quite a high profile within the town. Due to owning and managing a business John was usually very much in control of his life and of making decisions in most aspects of his life.

When John was diagnosed with multicentric glioblastoma his life took a very unexpected route, he was understandably very angry at the time of diagnosis. Initially his condition was thought possibly to be curative and his care and treatment were delivered at a regional specialist centre. The brain and central nervous system (CNS) Allied Health Professional (AHP) co-ordinator was very involved in John's care, he was also supported by the local community neuro rehabilitation team. It became apparent that John's prognosis was palliative, this news exacerbated John and Mary's emotional and psychological distress. It was at this point that the CNS AHP co-ordinator referred John to the Macmillan AHP team.

What did they do?

The team constitutes physiotherapists (PT), occupational therapists (OT), speech and language therapist (SLT), dietitian (DT) and assistants. John and Mary had been given a prognosis of 6 -18 months; he and Mary were devastated, their life was looking very different, they were losing control and felt cheated and angry. The initial support and interventions were from the OT and PT's within the team; and both John and Mary appeared to accept the physical assessments resulting in equipment provision, moving and handling advice / demonstrations and advice on adaptations. They were reluctant to accept any other forms of intervention at that stage. The team addressed each issue with sensitivity, the home was not the most conductive to adaptations, one example of this is that John and Mary slept in a four poster bed which potentially would have been difficult to adapt. John was also supported by the community palliative care CNS for symptom management. Advanced communication skills were utilised throughout the assessments and interventions. Some of John's expectations and goals were unrealistic and the team used highly sensitive communication skills to adjust those goals in a sensitive and realistic manner.

John's needs

John usually wanted treatment and interventions on his terms, and at specified times. On occasions he was keen to purchase his own equipment which was not

always appropriate for his needs. From the initial assessment it was apparent that John was experiencing communication difficulties but the PT and OT did not refer him to the SLT until they has built up a good relationship and gained John and Mary's trust and confidence of the teams input. As John's condition worsened he was assessed for mobility / handling, the team supported him through this time by visits, and phone calls to review John and Mary's needs. Mary found the transition from curative to palliative very difficult which led to challenging conversations with John and his family. John was discussed at the Gold Standards Framework (GSF) meeting and his condition / wishes communicated at future GSF meetings. John's case was also discussed at the hospice multi disciplinary team meetings.

Results

The team's input was very much led by John and Mary and the Macmillan AHP team were able to respond in a timely manner when requested. The SLT and DT were introduced when it felt appropriate; the additional interventions improved quality family time for John - conversations, lunch outings, holidays and days out etc. As a result of steroid treatment John developed diabetes, the DT offered extensive advice in this area; another side effect of the steroid treatment was Altered Body Image (ABI), John's body image was very important to him and the changes impacted on his psychological wellbeing. A Macmillan OT offered Cognitive Behavioural Therapy (CBT) to help John to adjust to such significant life changes. Throughout John's care the team discussed the sensitive area of Advance care Planning (ACP) and it was established that John would like to remain in his own home for as long as possible and he wished to die at home with his family around him.

Information was given at each intervention and when appropriate John and Mary were offered literature, websites and help lines provided by Macmillan Cancer Support.

When John was approaching the last few months of his life the Macmillan AHP team referred him to the district nursing (D/N) service, by this time he was experiencing increased difficulties in moving and handling, the Macmillan AHP team respected him as an individual and enabled John to do the things that were important to him rather than being nursed in bed as his condition deteriorated. Joint reviews were undertaken by D/N, OT and PT, it was organised for John to transfer to ground floor living, and the team requested an urgent assessment for equipment provision. The family wished to provide John's personal care; they set up a rota and the team taught John's family and friends about safe moving and handling.

When John's condition deteriorated further a profiling bed was ordered and a package of care from social services organised, he experienced swallowing difficulties and the SLT offered strategies to help with this. At the very latter stages John developed a chest infection and dying was diagnosed; he commenced on the Liverpool Care Pathway (LCP) and died comfortably and peacefully at home – the place of his choice, with the people he chose.

If you have any questions about this team's case study please email Macmillan development manager Teresa Karran TKarran@macmillan.org.uk