

Malcolm's story

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Co-founder – peoplehub





About Malcolm

- Turned 70 years of age in January
- Married for over 43 years
- Father to two children
- Spent most of his career in sales
- Retired in 2005 to spend more time with Anne (Malcolm's wife/my mother)

Becoming Ill - Initial Signs and Symptoms

- Withdrawal from activities
- Became more self-involved
- Some memory loss
- Confused and disinhibited

Complex needs

- Became doubly incontinent
- At high risk of choking (dysphagia)
- No longer able to understand what was being said
- Unpredictable behaviours and aggression

Diagnosis

- Started becoming ill immediately after retiring
- Was sectioned (3) in February 2008
- Diagnosed with right frontal lobe dementia in June 2008.
- Only one in every one million people suffer with this form of dementia

Care Package' s

- Discharged from hospital in 2008 under section 117 of mental health act
- Initially fully funded through health
- I became Malcolm' s full time carer
- Initially attended daycentre Mon – Thurs 8am – 5pm
- Started receiving Personal Health Budget in 2009

What helps dementia sufferers

- Consistency
- Routine
- Familiarity
- Living at home
- Clear and simple language
- Appropriate levels of medication

**Traditional services
weren't meeting any
of these needs!**

A new Care Plan – a new way of thinking

- It was asset based as well as looking at level of need
- Looked at what worked and didn't work
- Was a different kind of conversation & encouraged creative thinking
- No longer passive recipient of care
- Equal partners in decisions around care and support

Investment

- **Training** in having a new kind of conversation
– massive culture change
- **Time** to create a good care plan that works for the individual
- **Outcome** focussed rather than what it is that has been purchased and the cost of the item

How PHB was used

- Employed five members of staff at any one time to care for Malcolm
- We chose rates of pay for carers
- More flexibility in hours of support
- Malcolm and family involved in all of the decisions around his care
- Used for all of Malcolm's life needs, including health
- Purchased sky + box, rented a flat, bought a fence amongst others

Real risk – Money well spent?

Daycentre - £28,500

- Didn't understand his needs
- Generic activities
- Lack of choice
- Lots of anxiety
- Highly medicated

Sky + box - £35

- Provides choice
- Stimulates him
- Keeps him calm
- Keeps him engaged
- Keeps him safe

And finally

- Malcolm passed away in April this year
- Had consistency in his care until the end
- Staff understood his needs and communicated effectively
- Staff still visit the family regularly
- Had more choice in activities
- Spent all of his life living at home with his family, some six and a half years after being discharged from hospital