People with dementia and their families deserve personalised support

It’s not just about personal budgets:
• Information and advice
• Active and supportive communities
• Flexible integrated care and support in all settings
• Workforce: my support
• Feeling safe
• Personal budgets and self-funding
When it works well it transforms lives

What is important to Winifred

Her daughters Bernie and Maureen who visit daily.
Pat, her daughter, who travels up from London to visit and Marie who lives in Liverpool and visits fortnightly.

Seeing Kevin and David, who are Bernie and Maureen’s spouses – they remind Winifred of her brothers.

Her grandchildren: Terence, Emma and Ria. Also her great grandchildren: Grace, Ben, Harry, Zach, Charlie, Jack and Oliver. Winifred has a new great grandchild due later on in the year (June 2012).

Not to be around people who swear or are vulgar. Winifred visibly grows when complimented – do this often.

Her Roman Catholic faith. Winifred must say her prayers each morning and evening.
She adores cups of tea; milk no sugar.

Her rapport with Beryl. Winifred loves to be involved in household chores – folding the home’s laundry is a must and she loves to clean.
Kisses and cuddles. Winifred is very tactile and loves a hug. A big smile will draw her to you.

A diet which works for her. Good quality food has always been important to Winifred. She always loved Marks and Spencer’s food; fish, salmon, vegetables and a light breakfast.
Company is vital to Winifred. Spending time with others, especially Grace, Doreen, John and Joan, who live with Winifred.

How best to support Winifred

Be aware that Winifred is afraid of water. She does not/must not shower or bathe, but thoroughly strip washes herself each day with a supporter nearby.

Know that Winifred is often preoccupied in the morning. She must sort her room out before she does anything. Give her time and space to do this. She will appreciate you taking her a cup of tea whilst she does this.

Know that Winifred will worry about upsetting her tummy and needs to let things settle after eating. Always respect what she is telling you around this and go with her on it.

Winifred will eat a light breakfast, mid morning and loves to sit and chat as she eats.

If Winifred is reluctant to get ready for bed, to avoid her becoming distressed, divert her by talking about saying her prayers together with you. Ask Winifred to start you off as you have forgotten the prayer.

Know that Winifred is not a lover of TV and should be supported in ‘doing’. She will become bored and fractious if left sitting for long periods.

Winifred

What those who know Winifred best say they like and admire about her

A wonderfully, loving personality.
She brightens the room with her smile.
Her warmth.
Her beautiful nature and generosity of spirit.
She restores my faith in human nature.
There are problems to address

• Overcome barriers to personal budgets (awareness/dementia targeted information, dementia friendly process, transparency, raise expectations of professionals and people affected by dementia)

• Need a vibrant and diverse provider market that builds on best of person centred practice to genuinely enable self directed support
There are good practices and useful approaches that could become mainstream

Examples:

• Nottinghamshire County Council has over the last three years completely re-designed its customer pathway in order to embed personalisation. A specific initiative is being undertaken in partnership with the Alzheimer’s Society (AS) in order to improve the uptake and experience of personal budgets for older people with dementia.

• Stockport council are working with care home provider Borough Care and HSA to introduce far greater personalisation into the support received at Bruce Lodge, for example by checking current practice against the best personalised approaches and introducing practical improvements including matching staff and residents interests, using Individual Service Funds to create dedicated time for individuals to pursue personal interests and more..
Deeper and more strategic action is needed

Health and Well-Being Boards often have dementia amongst their priorities but need to go beyond traditional clinical activities:

• Integrated support at level of individual (PB/PHB)
• Personalisation from diagnosis not eligibility – early intervention and prevention
• Resilient communities that support and include
There are useful resources and materials