

Using one-page profiles to create care plans

Gill Bailey and Tanya Clover explain how one-page profiles can be used to deliver true person-centred care

Pioneers of the principles of normalisation such as Bengt Nirje and Wolf Wolfensberger argued that disabled members of society deserve an equal standing and should be held with the same regard as those without disability.

Person-centred thinking tools developed out of the processes of normalisation for people living with disabilities in the 1980s and '90s, spreading firstly across the US, then to the UK and eventually worldwide. The thinking tools are both a device and a process that can be used to drive and sustain change for individuals, teams, organisations, communities and ultimately society. Their ultimate goal is to really make a difference to someone's life and to ensure they have more choice and control through an ongoing loop of listening, learning and actions.

The UK has witnessed a raft of legislation over the past few decades, all aiming to raise standards of care and enable the individual to remain an active and valued citizen. This aspiration is embodied in the Care Act (2014). However aspirational, the Act does not go as far as Australia's Aged Care Act (1997) in asserting that care recipients "enjoy the same rights as all other people".

Whilst there is difference between the UK and Australian Acts, there is a commonality in the desire to deliver rights-based support in a timely manner in the place where the person chooses.

Citizenship and personalisation

One-page profiles are a person-centred thinking tool that can support people living with dementia in the transition from being passive recipients of care to their being recognised as full members of society. As aged and health care services aspire to give their clients more choice and control, one-page profiles help us progress beyond personhood towards citizenship and personalisation.

A one-page profile is a simple means of understanding three aspects of a person's life: 'what do people appreciate about me?', 'what is important to me?' and 'how is it best to support me?'.

By keeping the person visible, both physically and metaphorically, the meeting process of creating one-page profiles overcomes the previous rhetoric of inclusion created by the social model of

disability. We have seen these meetings generate innovative solutions to the situational challenges faced by people living with dementia, their families and those who support them.

We can do this for any person, regardless of whether they use words to communicate or not. We use other methods to listen carefully to what people are telling us and combine that information with the rich contribution families have to offer.

Winifred's story

Let us share the concept of one-page profiles through Winifred's story. She resides in a care home which supports 43 people who are living with dementia. Winifred is warm and loving with a beautiful smile, but when Gill first met her, she was on her knees at the locked gates of the home, crying and searching for her daughters.

As staff said she was often distressed and unsettled, the home's manager decided to develop a one-page profile with Winifred and her two daughters, Maureen and Bernie, to learn how to better support her. Gill facilitated the gathering of family and staff and it became a very different kind of meeting.

Winifred was able to contribute to the three aspects mentioned above – 'what do people appreciate about me?', 'what is important to me?' and 'how is it best to support me?' – in her own way, as much as she could, by telling us what a *good day* and a *bad day* looked like for her. Gill also explored *what was working* and *what was not working* from Winifred's point of view, from her daughters' perspective and also from the manager's perspective.

Looking at what made a good day and bad day for Winifred meant we could gain detailed information about what is important to her as well as clues about the support she wanted and needed. Exploring good days and bad days also provides information that can lead to immediate action, as staff supporting people have an instant record of how to help a person have more good days than bad.

We also asked Winifred's daughters, and other people who know her well, for their 'top tips' for providing great support. Learning the things that mattered to Winifred, what people liked about her and how best to support her began to populate

Winifred's one-page profile in a way that recorded the conversation rather than filled in a form. See Winifred's one-page profile (next page).

The value of one-page profiles

When looking at Winifred's original care plan, it showed only the staff's difficulties with caring for her and did not show Winifred. We believe that care plans rarely, if ever, highlight the positive, valued characteristics of the person and the rich detail of who they are.

In contrast, the one-page profile helps us to see their important relationships and connections, passions, hobbies and interests and in so much detail that you know the newspapers that matter to them or what their culture or faith means to them. This has intrinsic value far beyond the tick box plan on admission.

This depth of knowledge about what is important to someone is central to person-centred care and the very bedrock of personalisation. Looking at Winifred's one-page profile, you get a real essence of who she is. A one-page profile, therefore, is the foundation of personalisation. Without this information the person's limitations, difficulties and *dementia* will always be seen first.

Other one-page profiles

In a different example, Tanya facilitated a meeting for a gentleman who had lived in the care setting for just a few months. In all that time the staff had been unable to successfully offer him any support to meet his personal care needs. Whenever they tried, no matter how, he would become increasingly distressed.

At a meeting with his daughter-in-law we talked about what had made her successful in supporting him and what she did differently to the staff. She said she didn't know, but perhaps they sang the wrong songs. It was as simple as that. They sang. We asked what they sang together, and she said anything with bounce, *Daisy daisy* was a good one, but be prepared to sing it over and over.

The staff were sceptical at first, thinking

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 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.
- Having her hair done, going to the knitting circle.
- 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.
- Being busy, having a sense of purpose.
- Partying! Winifred says she has always loved a good party! She enjoys singing and music.
- Kisses and cuddles – Winifred is very tactile and loves a hug. A big smile will draw her to you.
- Fish and chicken are favourite foods. Winifred is not a red meat eater.
- A diet which works for her – good quality food has always been important to Winifred. She always loved Marks and Spencer's foods, 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.

Winifred's one-page profile



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

Image and profile courtesy Helen Sanderson Associates

How we can best 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 the need 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.
- Know that Winifred must feel useful – in a domestic sense is the strongest area, having plenty of jobs to do, having a role, for example looking after children.

it was too simple, but agreed to give it a try. It worked immediately. From that day, staff have been able to support this gentleman with all his personal care needs and his daughter-in-law has felt able to just enjoy spending time with him.

In another meeting, staff mentioned that a gentleman was being "very fussy" about food and drink, eating ravenously some days and on others, seeming disinterested in any food or drinks. Tanya observed that he paid attention when some participants contributed, but seemed uninterested when others spoke. A simple change of positions showed he could neither hear nor see clearly on his right side. Further questioning led Tanya to guess that the man's days of enforced fasting occurred when staff inadvertently placed food on that side. The solution was obvious and, once captured on his one-page profile, the effect was immediate.

Creating one-page profiles

Historically we know that care services pay great attention to what is important *for* people, focusing on what it takes to keep people healthy and safe, whilst what is

important *to* people is often seen as something we do if we have enough time or enough staff. Personalisation brings this back into balance. Recognising that people are the experts in their own lives means we must know and pay attention to what matters to people to deliver support in the context of how people want to live.

Developing a one-page profile is more like being a detective than doing a questionnaire. It is not just finding the answer to a question, but also trying to establish the level of importance attached to an answer, or what an answer tells us about the help and support a person needs in their life. To do this we always have to ask follow-up questions, but we never ask "why?" "Why?" is a request to justify and explain. A better question to ask is: "Tell me more about that...". We want to start a conversation, to learn about what matters to the person from their perspective. The goal is learning deeply, not getting through as many questions as possible.

One-page profiles consist of questions that are deceptively simple. Experience tells us that asking direct questions rarely works. Merely asking a person or their

families "What is important to you?" and "How do you want to be supported?" is unlikely to lead to the rich information we need. Equally, seeing a one-page profile as another form to fill out does not do the process justice.

Instead the information for a one-page profile is drawn out through in-depth conversation and learning about people in different ways. The profile is simply a way to record the wealth of information we gather.

Ask yourself: "If I had only two minutes to share my top tips about supporting the people I love to live well, what would I say?" Now read through your care assessments. Is there a question there that would get that answer?

If we want different answers, we need to start asking different questions. Importantly, a one-page profile offers the *structure* to ask different questions and listen differently to the answers.

Part of care planning

One-page profiles are also not a 'one-off'. As soon as we have produced a one-page profile for a person that truly reflects them,

we need to ensure we are continually listening, learning and acting on the information so that their one-page profile grows and evolves with them and stays truly reflective. As the information gathered by both the working / not working person-centred thinking tool and the one-page profile process are regularly updated, they are a fantastic resource to use when action planning.

One-page profiles are fundamental to the care planning process. They become our job description and help us to be aware of what needs to be present on a daily basis. It ensures that people are consistently supported in a way that makes sense to them, truly enhancing their choice and control because those supporting them follow their one-page profile. Knowing what is important to people and knowing how best to support them from *their* perspective also means that truly personal and achievable outcomes for the person can be created.

Ultimately, one-page profiles are about supporting a person to have as much of a normal way of life as possible. Ensuring this happens moves service providers away from those care plan boxes that often focus only on a person's physical needs, without paying good attention to what matters to people.

Conclusion

Our quality of life is determined by the presence or the absence of those things which are important to us and so we have to take this into account when providing support.

Personalisation and the process of implementing one-page profiles has taught us that we need to stop reflecting on what we have achieved in dementia care today and begin to run towards what we can achieve in the future. Better still, in the words of Christine Bryden (2005) "let's dance" our way there. ■

More information about one-page profiles and person-centred thinking tools is available at: www.helensandersonassociates.co.uk

References

Bryden C (2005) *Dancing with dementia: my story of living positively with dementia*. London: Jessica Kingsley Publishers

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Real culture change: the Butterfly Care Homes experience

In the lead-up to his Australian speaking tour in June, **David Sheard** outlines the Butterfly Household Approach to achieving real culture change in dementia care homes, based on a model of emotional intelligence as the primary competency

In the UK, where I live and work, every care home brochure now states that it provides person-centred care and the term has moved into everyday usage. This has occurred without care homes grasping any real understanding of the significant degree of culture change necessary to achieve this and what is required to truly implement person-centred care. This article summarises the UK evidence in developing Butterfly Dementia Care Homes and the strategic lessons and implications for changing cultures of care.

The adventure begins

In 1995 I left the UK National Health Service where I was general manager of dementia care services, vowing "I won't run factories in dementia care anymore," and embarked on the biggest adventure of my life. That year I founded Dementia Care Matters, now a global dementia care culture change and training organisation, and developed the Butterfly Household Model of Care.

The first Butterfly Household began in 1995 with a care home of 36 people living with dementia at Merevale House in Atherstone, Warwickshire, UK. The model of care, not previously tried, was based on some simple, fundamental beliefs that people living with a dementia can thrive well in a nurturing environment where those living and working together know how to 'be' person-centred with one another.

There was no 'them and us' distinction between people living and working together. Instead the focus was on the importance of people's emotional memory, helping them to be who they were and through knowing the person's life history, understanding that at times they will be experiencing and living defining emotional moments from their past. Rooms were filled with the stuff of life – domestic items, work-related objects, things relating to the locality, family

events and themes from the past. This helped people living with a dementia to be who they were by validating their reality, supported by an approach which emphasises being loving and a real sharing of each other's lives.

The Butterfly Household Model

The essence of the Butterfly Household Model of Care rests on four key beliefs – first, that it is possible to restore people's positive emotions and identity on the inside, enabling people with a dementia to come alive again.

Secondly, that this requires a whole new approach to recruitment, training and appraisal of staff which focuses on the development of people's emotional intelligence as the primary competency in dementia care.

Thirdly, that this requires, at a strategic level, an organisation to first show it knows how to become a person-centred organisation itself, before trying to foster person-centred care in others.

Fourthly, that to achieve the above, residential aged care homes need to be physically divided into recognisable self-sufficient domestic houses.

We use the symbol of a butterfly formed by two hearts to represent people living and working in a residential aged care home coming together to create, like a butterfly, moments of connection, colour and transformation in each other's lives.

Since these early beginnings, over the past 20 years the Butterfly Household Model of Care has grown across the UK and Ireland, more recently moving into Canada. Care homes are supported to undergo a one-year culture change program known as a Butterfly Project, incorporating three elements – leadership consultancy, house leader / nurse coaching and the 'Being A Star' staff program.

Currently there are 65 Butterfly Projects and hundreds of care services across the UK adopting the approach. ➤