Using Personcentred Thinking to implement Dementia Care Mapping

Alison Morley, Diane Redburn, Wendy Jennison, Jackie Mascall, Jane Fryer, Helen Sanderson, Gill Bailey

May 2010



Contents

Introduction
Dementia Care Mapping - giving people a real voice
Old style dementia mapping report5
Person-centred thinking - at the heart of personalised care5
Combining Dementia Care Mapping and Person-centred Thinking to deliver real change
Putting it into practice - Emily's story9
Conclusion11
Examples13

Introduction

One size can never fit all. We normally hear that when people talk about clothing, but the same could be said for care and support. While councils are busily adopting tools and processes to personalise services, they must ensure that they way they use those tools makes their services more personal where it really counts - at the point that people experience them. Good quality plans, strategies and reconfigured services are all vitally important, but if someone's immediate carer isn't working in a truly personcentred way, then none of the high level strategies make much difference - at least not to the person on the receiving end.

Hull City Council had been developing its workforce so staff had practical person-centred thinking skills and tools to help them deliver more personalised services¹. Some of those who undertook the training were also experienced in Dementia Care Mapping: a process that helps professionals observe life through the eyes of a person with dementia. They saw that the two approaches could be combined to provide rich, high quality information to enable people with an advanced dementia express themselves. This in turn could help the staff who support them deliver more personalised care.

Buckinghamshire County Council has been working with Bradford University since 2005 to train Dementia Care Mappers. Their person centred planning lead Jackie Mascall had started to explore using person centred thinking with people who have dementia through the Practicalities and Possibilities² programme in 2008. Jackie worked with Dementia Care Mapper, Jane Fryer and the local mental health trust's clinical psychologist Jane Fossey to develop a training programme that enables care homes to achieve a more personalised approach when developing care plans, using person centred thinking tools. This course shows how the useful information gathered through Dementia Care Mapping can be translated into a meaningful One Page Profile to Action for the individual.

Gill Bailey, lead on person-centred thinking and older people at training and development consultancy Helen Sanderson Associates, delivered Person-centred thinking training in Hull and worked with people in both areas to connect and share what they were trying. This paper draws that learning together and demonstrates how person-centred thinking tools can enable Dementia Care Mapping to deliver significant change for people who need care and support, and the teams who deliver that support.

Dementia Care Mapping - giving people a real voice

Dementia care mapping (DCM)³ is a process that helps a professional observe life through the eyes of a person with dementia. It involves watching someone unobtrusively over an extended period of time to see how they respond positively and negatively to events that happen to - and around - them. The results of DCM can change the way the person with dementia experiences care and support, while also assessing the staff who deliver that care and identifying staff training needs.

During a DCM evaluation, a "mapper" will sit with a group of people in the communal areas of a care home. They will to observe up to five people with dementia, continuously over six or seven hours. After each five minute period, the mapper will note the behaviour, mood and engagement of the person/s they are observing.

All interaction is recorded, including personal enhancers (any interaction that has a positive experience on the person and their well-being) and detractors, which have the opposite effect. Anything that provokes a strong reaction is recorded as highly enhancing or highly detracting from well-being⁴. This raw data is then analysed by the mappers and recorded in a recognised format.

Once the initial exercise has been completed, the mappers return to the care home to give staff feedback on the results. This is done in a variety of ways including role play, PowerPoint slides, written presentations and group discussions. Staff members are encouraged to take ownership of the report, and with the support from their managers, look at how they can improve the quality of care, interactions and well-being of the people living in the home.

However, learning from this process has shown that care home staff members do not always understand the DCM report, or the importance of acting on its observations. Feedback from staff in Hull suggested they found the reports complex and full of jargon and consequently, not much action was taken after the mapping exercise.

Hull City Council addressed this issue in 2008 by supporting their dementia care mappers to become accredited trainers in person-centred thinking skills. Hull recognised that these tools could help interpret the results of the DCM in a way that made sense to those staff members supporting people in care homes. Additionally, the rich information the maps provide can then be captured in an individual's "one page profile", which describes those things that really matter to a person.

Following accreditation, the mappers returned to the care homes to train care home staff on person-centred thinking tools. They focused on showing how the information from DCM could be incorporated into their everyday work. Using tools like "what is working and not working" and "histories", care home staff could collect people's personal histories and preferences. They found out what was important to and for each person and what 'best support' looked like from that person's perspective. They also built better relationships with the people they supported and their allies. It also helped explain different people's behaviours, for example, the lady who would constantly fold things had once run a laundry.

It soon became clear how successful this approach was going to be and people's lives really began to change. The authors share examples further on in this paper.

Old style dementia mapping report

Personal Enhancers and Detractors Observed for X

Comfort

PE 1 - Warmth (highly enhancing). X was sensitively escorted to her room by members of staff for personal care. The staff members used touch to reassure X and interacted with her throughout.

Identity

PD 4 - Infantilization (detracting). A member of staff who had been assisting X to eat roughly wiped her mouth area with the protective apron she was wearing. There was no interaction and it was observed that X's mood level - which was initially positive - decreased to a negative level.

Occupation

PD 13 - Objectification (detracting). X was escorted to the dining table for a meal. X was not given any choice of where to sit and no interaction occurred. X had a protective apron placed around her neck without any explanation and then sat down.

PD 13 - Objectification (highly detracting)

X was assisted to eat her meal with no choice, explanations or interactions throughout the courses. The member of staff interacted only with other staff members and made no attempt to include X in conversations. It was noted that X's mood level showed a decrease at this point.

PD 11 - Imposition (detracting)

X was given a cup of tea and biscuits with no choice of what she wanted. They were left out of her reach until a member of staff returned a little later to assist her. There was no interaction with X. This was a missed opportunity to increase X's mood levels from a negative state to a positive state while assisting her.

Inclusion

PD 15 - Ignoring (detracting). Members of staff were sat in the lounge where X was and were recording in the resident's files. X was not responded to when looking for interaction. The members of staff did not interact with any of the residents in the lounge. This was a missed opportunity to engage with the residents so increasing their well-being.

Person-centred thinking - at the heart of personalised care

Put simply, person-centred thinking and planning is evidence-based practice⁵ that assists people in leading an independent and inclusive life. The Department of Health recently issued the guidance Delivering Personalisation through Person-Centred Planning which describes the process as a way of asking what people want, the support they need and how they can get it. Person-centred planning is both an empowering philosophy and a set of tools for change at an individual, team and organisational level. It shifts power from professionals to people who use services⁶.

The foundation of person-centred planning is a range of simple, practical person-centred thinking tools. These can be used to create day-to-day change for people using services, as well as building a person-centred plan. First line managers need to understand person-centred thinking tools and coach their staff in using them to deliver self-directed support.

Combining Dementia Care Mapping and Person-centred Thinking to deliver real change

Hull's dementia care mapping team saw that the rich information from a dementia care map could be more easily understood by care home staff if it was shared through using personcentred thinking tools. This would give care home staff the opportunity to change the way they supported the people they worked with.

Take Jenny's story for example. Jenny has lived in a residential home for the past six years. She has dementia and staff members were finding it difficult to cope with her behaviours. She wandered around the home day and night punching staff members, other people living in the home and the walls. Three staff members were required to support Jenny when she needed assistance with personal care but she would constantly hit out at them. When Jenny was not walking about the home, she would remain in her bed all day and refuse her medication. Jenny would not let staff near her and refused all physical contact. During this time, she never communicated

verbally. The situation saddened the staff and they felt that they were letting Jenny down. They were barely meeting her basic human needs and she had no quality of life.

In November 2008, the home asked two dementia care mappers to map Jenny so they could seek ways to understand her. The mappers spent two days observing Jenny as she walked around the home. The results of the map were shared with the care staff of the home. They found there was very little interaction with her. But when care staff did speak to Jenny, her mood rose and she would smile. She also appeared to enjoy rubbing the wall paper and her clothing, which were textured. It was noticed that Jenny interacted with music that was playing by clapping and singing along to it. The mappers also observed that Jenny picked up a bundle of towels and carried these around with her.

Mappers that use a person-centred approach to analyse information in a Dementia Care Map use the "Working/ Not Working" tool. This provides a way of presenting enhancing and detracting factors, interactions and events as things which were either working or not working for an individual. They do not dismiss the referencing of enhancers and detractors - they give people both - but their interpretation of it using the working/not working tool helps support staff more easily implement the rich learning they have now gained.

Discussion took place with the staff to explore how Jenny's quality of life

could be enhanced. The mappers described how use of their personcentred thinking tools could support the staff to use the learning from the map to make a real difference to Jenny's life. Staff explained that because of the home's routines, they had not noticed what Jenny was actually doing other than walking around. They were constantly asking her to sit down to keep her safe. Once staff members were able to understand Jenny's behaviour, they were able to suggest potential activities around the home that Jenny may like to do. Staff members' ideas included a tactile/rummage box - to meet Jenny's sensory needs -and to find out what type of music Jenny enjoyed.

At subsequent mapping exercises in other care homes, both Hull and Buckingham's mappers used the "Working/Not Working" tool to explain the results and next steps for the care home managers and their teams. They agreed an action plan for taking the information they had learnt in the mapping process and used it to change the way they supported people. This included the mappers returning to coach the staff in the use of further person-centred thinking tools like "histories", "one page profiles" and "learning logs".

Staff members asked to explore Jenny's life history, as this could explain some of her behaviours and would also to find out what her interests and hobbies were. They found out that she loves Mars Bars and when she lived in her own home she would buy them in bulk. Staff can use the "Histories" tool to gather information about who the people they are supporting have been in the past and what matters to them. This can then be used together with the Dementia Care Map to build up a person's one page profile. These profiles capture information about what is important to people and how best to support them from their perspective. Specifically, it is a summary of what keeps a person healthy, safe and well; what makes them happy, content and fulfilled; and what good support looks like. One page profiles may also capture some of the things others appreciate about the person, their gifts and qualities, rather than focusing on their medical condition, label or what is wrong with them. The one page profile must grow and evolve over time into a personcentred description based on continual listening and learning.

Learning what was important to Jenny and what great support would look like for her would ensure that she had a better quality of life. A one page profile was developed with Jenny, her staff and her family and the learning from the map was included on this. They found that touching and feeling things was really important to Jenny. She holds a piece of ribbon and will run it through her fingers when staff members are assisting her in the mornings.

Observations about a person's behaviour from the dementia care map are recorded on to a learning log. If the recorded learning indicates that a particular activity has a positive effect on a person's well-being, it is reflected in their one page profile as being important to them. If something is shown to have a negative effect, and it cannot be avoided, then this is recorded in a way that describes how best to support them. All information must be continually updated through constant listening and learning, to ensure the one page profile is kept 'live'.

Over the past year, staff members have become more aware of how Jenny is getting those little things that are important to her. There has been a real change in Jenny's behaviour and both her family and other agencies involved with Jenny have commented that she is a new woman. Jenny appears content and is involved in meaningful activities around the home such as folding the laundry. The manager explained that when the initial map took place, Jenny would not even go outside but now she loves to walk around the garden with staff.

If during the mapping process, a person finds it difficult to communicate, then a communication chart is introduced. This is a powerful but simple tool that records what a person is saying with their behaviour and how people should respond in a way that makes sense to the person.

Jenny's one page profile explains that when Jenny tells you she hates you, it is because she is frightened. This sometimes happens when she hears loud noises. Reassure her and stroke her arms.

Between six months and a year after the first dementia care mapping exercise, a second map is carried out. The mappers returned to map Jenny again a year later. The results of the map showed a real improvement not only in the home environment, but also in Jenny's well-being and happiness.

In Hull, the results so far have shown that staff members gain an appreciation of the people they support, and of each other. People say they feel revitalised in their roles and can appreciate each person's uniqueness rather than their condition. One page profiles can also be developed for all of the people who have been 'mapped', as well as the staff team and managers. This helps to let each other know what is important to each of them at work and how their colleagues can best support them. while providing a way to review what was working and not working for each of them at supervision or team meetings.

Each time the mappers returned back to Jenny's care home, they observed that real changes started to happen within the home; both in the environment and the staff culture. Staff members appeared more motivated and interested in the people they supported.

"We've learned more about the person. You think you knew the person before but you didn't really." Support worker

"The mappers' suggestions and pointers using the person-centred tools support the map to move forward. We didn't know what to do with it before." Shift leader "We thought we were doing the best we could until we found out what was important to the person." Support worker

"The dementia care map on its own was brilliant. It helped us to think about activities for the people living here, but now, it has now made such a difference to find out what is important to individual people." Registered manager

"The format we have now has surpassed our expectations by providing us with a more simplistic and easy to understand approach. The person-centred thinking tools give clear and concise information that is easy to read. This approach is now the way forward in our delivery of a far better service that combines personcentred thinking fully." Registered manager

In Hull's experience, the mappers observed a change in the way staff and the people they support interact with each other. This gives a measurable increase in enhancing people's care and support experiences, making a significant difference to the lives of the people living in the care home. Far more importantly, there were small but significant changes in the lives of people living at the residential home as Emily's story will show.

Putting it into practice -Emily's story

'There's no point having a life if you can't live it.'

Emily is in her early nineties and has lived at the home for three years. She has three sons and a sister, Margaret, who visits her at least twice each week. Emily loves Margaret's visits as she brings her treats such as cakes and trifles. Emily has been a great traveller in her lifetime. She loved to be abroad in the sunshine. Emily is described as determined, independent, fun to be with and a real character.

Emily has advanced dementia and was included in a mapping exercise. The mappers observed positive events during her day, for example, when she showed signs of discomfort and pain in her shoulder area, staff recognised this and offered her comfort by gentle massage as well as pain relief medication. Emily's mood was visibly seen to rise whilst have her shoulder massaged. However, the mappers also observed Emily asking staff on several occasions if she could go out and was told each time she could not. Emily was sat in a large communal lounge and the furthest away from the window. The room was dimly lit by a low energy light bulb.

Emily had a velvet cushion and was observed to gain great pleasure from stroking it. Staff did not realise this and constantly removed the cushion and placed it at her back. It was done with good intent but each time it happened Emily displayed visible signs of ill being. The mappers also saw that when Emily was supported to eat and drink independently, she would be highly engaged. However on other occasions when she was given a feeder cup and spoon fed her meal by staff her mood would lower into a negative state.

Emily was also observed folding the pages of a magazine and rubbing tea

and biscuits into it. She was highly engaged and her facial expression indicated that she was gaining immense pleasure from this activity. Unfortunately staff perceived this as dirty and told her so before removing the magazine. Again, Emily's mood and engagement level lowered considerably.

During the feedback session, the mappers supported staff to explore what Emily's behaviour was saying using the "Working/ Not Working" tool. Considering the learning from the map they identified that what was important to Emily and how best to support her from her perspective. Emily, staff members, family and friends were involved in developing her one page profile. They captured what those who knew Emily appreciated about her. Staff began to understand that Emily's velvet cushion met her psychological need for comfort and increased her wellbeing. They knew this because her face lit up when stroking the cushion. This information was transferred to Emily's one page profile.

The mappers helped the staff expand the one page profile and introduced them to other tools, like the learning log or the communication chart as and when they would be useful or would help solve a problem. When staff were able to see that when Emily was eating and drinking independently her mood and engagement levels were raised considerably, they understood that this was important to her. They recognised that great support for Emily would be the occasional verbal prompt when her attention was distracted from her food. This information was captured under the one page profile headings of "Important to Emily" and "How best to support Emily".

Using the "Histories" tool, the staff talked to Emily's family and found she was a sun lover. Emily had always spent the majority of her time either out in the garden during summer and abroad in the sunshine during the winter. Previously, staff had been unaware of how important it was to Emily to spend time in the sunshine. Again this rich information was captured on her one page profile. It made a huge difference to Emily to be able to sit in a chair by the window, looking out to see and feel the sunshine.

From the learning gathered in the map it was clear that Emily derived a lot of pleasure from sensory stimulus (touch, folding, rubbing and stroking). Staff helped Emily develop a tactile/ rummage box and the learning from observing Emily in this activity was recorded on the learning log. Staff members were coached to capture anything that Emily enjoyed and where her mood and engagement increased on the "What is important to Emily" section of the one page profile.

As staff had already recognised when Emily was in pain with her shoulder a gentle massage and offering pain relief worked well, this was captured under "How best to support Emily". Capturing this information enables other staff, especially those who may not know Emily well, to quickly ascertain the things that are important to Emily and what great support looks like from her perspective. Since this approach was introduced alongside dementia care mapping, the mappers are now observing Emily being supported to sit by the window as well as going out into the garden on fine days. Staff members ensure Emily has her velvet cushion, her rummage box and she is supported to eat and drink in ways which make sense to her. Emily's mood and well-being have improved significantly and the staff started to use the Person-centred Thinking Tools with other people.

The mappers also noticed a change in atmosphere at the home. As people started to experience the little things that meant so much to them, their moods rose. And when the moods of several people started to rise, the atmosphere became "lighter and happier". Staff were interested in finding out the little things that really mattered to the people they supported.

Over the months there was a real shift in culture within the home and it was observed that the sense of "power" was with the people living there, rather than over them. The residents are being listened to whether they use words to speak or not. Staff members understand that the presence or absence of those things which are important to people determine their quality of life - they are now clearly recorded and shared.

The manager said the team's motivation and commitment had gone through the roof. When it was fed back to them how much they'd helped people get a better quality of life, one of the staff remarked 'There's no point having a life if you can't live it.'

Conclusion

As part of the dementia care mapping process, a summary sheet is compiled; this shows the amount of personal enhancers and detractors observed. As the mappers return to the homes a year on from the initial DCM, they are now seeing the real benefits of combining DCM and person-centred thinking tools. There is clear evidence that the number of personal detractors has lowered and that personal enhancers have increased. When the things which are important to people are present and they are supported in ways that make sense to them, there is a significant increase of well-being in the person.

Hull is planning to continue offering DCM to residential care homes and will coach the staff in person-centred thinking. Their action plans state they will develop one page profiles for those residents included in the map and conduct a remap at a later dateusually 9 months to a year later. They hope to include the original mapped residents so that they can compare the results with the previous map. Hull will also facilitate Champions' Meetings where we can all share good practice, advice and support each other.

In Buckinghamshire, Bradford University has recently delivered training to a group of staff to refresh their Dementia Care Mapping knowledge. Jackie and Jane then delivered their training to show these mappers how to translate the information obtained through mapping into a meaningful One Page Profile to Action for individuals. The representative from Bradford University stayed to find out more about person-centred thinking tools and how the two related. A DCM Support Network has also been set up by a local provider to keep knowledge up to date and share good practice.

References

Perrin T, May H and Anderson E eds (2008) Wellbeing in dementia: An occupational approach for therapists and carers. Edinburgh: Churchill Livingstone.

Brooker D and Surr C eds (2005) Dementia Care Mapping: Principles and Practice. Bradford Dementia Group: University of Bradford.

Notes

- 1 For information about the Transforming Teams programme, please visit www. helensandersonassociates.co.uk
- Bowers H, Bailey G, Sanderson H, Easterbrook L, Macadam A (2007) Person Centred Thinking and Older People - Practicalities and Possibilities, Helen Sanderson Associates
- 3 Dementia Care Mapping was developed by Professor Tom Kitwood and the Bradford Dementia Group at the University of Bradford in 1992. http://www.brad.ac.uk/ health/dementia/
- 4 Brooker D and Surr C 2005 pp35 36
- 5 Robertson J, Emerson E, Hatton C, Elliott J, McIntosh B, et al. (2005), The Impact of person-centred planning, Lancaster University: Institute for Health
- 6 Sanderson H (2010), Personalisation through person-centred planning: guidance for delivering Putting People First, Department of Health

Examples - Jenny's one page profile

What is important to Jenny

Jenny loves all types of music, she will sing, dance, clap her hands and tap her feet to the music.

To talk about her son-in-law Martin and be listened to well – sit with her.

Touching and feeling things really matters to Jenny; she has her own basket with different fabrics in.

Jenny enjoys tea and coffee in a mug, milk with one sugar.

To eat her meals in the lounge, the dining room doesn't work for her.

She has a great appetite and loves anything sweet especially puddings and Mars bars.

Jenny enjoys a bubble bath; she doesn't mind which product as long as there are bubbles!

Jenny must have a walk around the garden each day.

To sit by the window

To get up between 9am and 9.30am – no earlier.

To be called Jenny, not Jen or pet names this would irritate her.

To hold her piece of ribbon when getting ready each morning



Jenny

What those who know Jenny say they like and admire about her

Thoughtful Caring A real character Affectionate Loving

How best to support Jenny

Know that Jenny will not respond to you if you do not include "Jenny" in the sentence when speaking to her. When Jenny tells you that she 'hates you' it is because she is frightened, this sometimes happens when she hears loud noises, reassure her and stroke her arms.

When Jenny has her medication, stay with her as she chews her tablets and needs encouragement to drink plenty of fluid with them – orange juice is favourite.

Jenny's drinks must be served in a mug.

Know that Jenny holds a piece of ribbon when getting ready each morning and will run this through her fingers whist staff assist her to get ready in the morning.

When walking to the toilet with Jenny she sometimes backs away from the toilet door, she must never be forced, leave it and go back later.

Jenny's bubble bath and toiletries are in her bedroom, these should be kept on the top of the wardrobe. Jenny has eaten and drunk these products and this causes her to have an allergic reaction.

Examples - Jenny's working/not working



Examples - Jenny's communication chart

What is happening/where/ when	When Jenny does this	We think it means	We need to do this
Anytime	Puts her clothing into her mouth	She is thirsty	Offer her a drink - tea or coffee with a drop of milk onesugar is favourite - must be in a mug
Meal times	Doesn't lift her knife and fork, looks at her plate	She needs help cutting some of her food	Jenny is embarrassed that her fingers are bent with arthritis - sensitively offer to cut her food - quietly
Going to the bathroom	Backs away from the bathroom door	Jenny is anxious	Leave it and go back later
When using the lift	Begins to shout	The gap between the floor and the entrance to the lift makes her anxious	Reassure her and link her as you get into the lift

Examples - Emily's important to/for



Examples - Emily's one page profile

What is important to Emily

Most important to Emily is that she sees her sons Paul and John twice a week and her sister, Linda who visits twice a week.

Emily enjoys a hot drink of t ea, a drop of milk with one sugar – and plenty of it!

Emily is very proud of her appearance and loves to have her hair set each Wednesday afternoon.

Emily's face lights up when you hold her hand.

Stroking her brown velvet cushion. Emily must have a brandy and dry ginger each evening.

Walking outdoors is a real highlight for Emily. Going outside into the sunshine whenever it is out.

Emily loves old pub songs and war time mu sic; she has a CD with these on.

Emily is the life and soul of any party. Members of a local church visit ing with their cat every Monday ; Emily loves the cat and enjoys stroking it.



Emily

What those who know Emily say they like and admire about her

Sense of humour Determined Kind Good-hearted Caring Fun to be with A real character

How best to support Emily

Speak into Emily's left ear – see Emily's communication charts to understand better what she is telling us.

Emily's cups of tea must be hot. If Emily appears to be in pain Offer her pain relief and massage her shoulder.

Emily may need reminding to eat her meals but never take over. If Emily is distressed a hug or holding her hand works well.

Emily's food MUST be blended. Support Emily to go outdoors when the sun is shining – know that she is happy to sit out in the garden on her own.

Never take Emily's brown cushion off her, she derives great pleasure from stroking it.

Ensure Emily is offered her brandy and ginger around 8pm each evening.

Examples - Emily's working/not working



Examples - Emily's action plan

Who	Will Do What	By When
Claire and Jane	To complete a life story book with Emily and her family/friends .To discuss with Emily and her family her past hobbies, interests and employment. Create a memory/ rummage box for Emily.	To be started by end July og
Carol	Explore the use of hand massage and sensory equipment	Feedback on progress at August 09 staff meeting
Susan	Ensure that all staff are using Emily's one page profile to support her well and explore in individual supervision sessions how we can include more of the things which are important	During all supervisions as from 1st September 2009
Dementia Care Mappers	Complete person centred tools: Important to/for Emily to one page profile to WW WNW to Action; Coach staff to understand person centred thinking and use of the tools in order to grow and action the rich information gathered	1 August 2009