A Better Life for people living with dementia in the community

Sample stories and recorded outcomes for people with dementia and their carers

Practice examples collected from dementia practice co-ordinators in North Lanarkshire

April 2015

Background

These short stories were gathered during a project with dementia practice co-ordinators in North Lanarkshire in 2014. The practitioners involved represented the NHS, the local authority team for older people and integrated day services. The practitioners were involved in a national test of the 8 pillars model of working with people with dementia. The project also explored the 7 principles of the Joseph Rowntree Foundation body of research A Better Life for Older People.

The practitioners involved in the test site wanted to be able to track outcomes as part of their work. The key reason for collecting these stories was to find common ways of recording outcomes across professional boundaries. The stories have been anonymised but are based on real people with dementia living in the community, and each is followed by a table identifying selected personal outcomes. In three cases, outcomes are also identified for a family carer. It should be acknowledged that these stories were shared as examples of good practice. The outcomes were particularly positive in these cases and they are not intended to be representative.

Two of the examples included here have also been published in a more general guide to recording outcomes. The focus of the guide was not on measurement of outcomes (via scale measures) but on writing narrative about personal outcomes. That guide was produced as a result of Meaningful and Measurable project. Working with a range of practice partners, this project identified core criteria for good recording of narrative outcomes data as follows:

Core criteria for outcomes focused records

Distinction between outcomes and outputs	x
The outcome is personalised	x
The person/family has a role	x
Uses person's own language as appropriate	x
Action oriented (usually)	x

To provide an illustration of how the criteria relate to recording, the first example below is followed by a table which pulls out details of the record, as they apply to the criteria.

1) Mary McPherson

The following example includes extracts from two reviews from different points in time, and illustrates how changed circumstances for the individual concerned promote discussion about how Mary's personal outcomes can be maintained

Mary McPherson is a retired shop assistant who lives alone and has vascular dementia. She attends an integrated day service three days a week, where close attention is paid to her fluctuating health conditions. Social interaction at the centre also helps to reduce Mary's anxiety. Staff noticed a changed pattern of behaviour. Although Mary was usually even tempered and enjoyed group activities, she had been unsettled. Staff noticed that she could be irritable in the morning, and that if the day started like that, Mary could really disrupt activities. This led to uncertainty about whether the service was still meeting Mary's outcomes.

Following a staff discussion, it was decided that if Mary was irritable in the morning, a senior staff member would give her one-to-one time and try to get to the root of the problem. Staff used verbal and non-verbal cues to work out what was going on. It became clear that Mary was anxious about problems with her neighbour's children. She also becomes agitated when her niece Angela is away. One to one chats provided Mary with reassurance and helped to reduce her anxiety. Staff now take a pro-active approach when they know Angela is away and provide extra support and reassurance.

FIRST REVIEW
Personal outcome: Seeing people
Mary enjoys mixing with everyone at the day service although recently she has been unsettled
Personal outcome: Having things to do
Mary enjoy participating in group activities but again has been struggling with participation recently and has been disruptive by shouting and swearing
Personal outcome: Being as well as you can
Mary has fluctuating health conditions which are monitored and managed at Sinclair. It is not clear how this would be managed elsewhere. Usually attending the service helps to reduce her anxiety through avoiding social isolation. However Mary has shown signs of anxiety and agitation recently which is impacting on her participation in Sinclair
Action
Staff have had a meeting to discuss the fact that Mary has had days where she was agitated and at times disruptive. The decision was to provide one to one time to Mary to talk through her concerns at the start of a bad day
What else needs to happen
The centre manager is asking community police to drop in and visit Mary to reassure her about her worries about her neighbours

SECOND REVIEW
Personal outcome: Seeing people
Mary is again enjoying mixing with her friends and staff since the new approach has been adopted of one to one time as a response to agitated behaviour
Personal outcome: Having things to do
Mary enjoys group activities again

SECOND REVIEW
Personal outcome: Making a contribution
Since staff have been observing Mary more, they have noticed how much her face lights up as she enjoys helping to share out materials when there is a craft activity
Personal outcome: Being as well as you can
Mary's health conditions can continue to be monitored and managed at Sinclair. Staff have commented that Mary seems less anxious, more settled and contented. Angela now informs staff in advance if she is going to be away. Mary communicates with staff after one to one chats by patting their hand, which seems to be her way of saying that she feels less anxious

Again, the criteria can be applied to this example as below

Applying the criteria	
Distinction between outcomes and outputs	Attendance at the integrated day service is the key output or service for Mary. It links to outcomes including maintaining wellbeing, providing social interaction and reduced anxiety
The outcome is personalised	Specific details relevant to Mary are recorded against each of the relevant high level outcomes
The person/family has a role	Mary enjoys and benefits from sharing out material for craft activities
Uses person's own language as appropriate	Mary retains some ability to communicate verbally. Staff have also used observations of changes in Mary's behaviour to monitor her wellbeing and recorded that she pats their hand to reassure them that she is ok
Action oriented (usually)	A range of actions are identified to maintain outcomes for Mary

2) Jim and Anna

Another example from integrated day services includes outcomes for the person and the carer being considered in tandem. This example is an extract from a review, showing similar types of outcome for the person and their carer, although the personal outcomes are different.

Jim has had dementia for several years. He lives at home with his wife Anna. Recently his dementia has advanced and he has struggled with mobility. Jim was unable to get out to the day service a couple of times last month. Jim enjoys the company there and Anna relies on Jim attending so that she can have time to spend with their grandchildren. The manager suggested a stairmatic to help Jim in and out of the house. However, Anna was not happy with this suggestion. The hall is very small and the stairmatic would clutter the hall and living room. After further discussion, agreement was reached to provide an extra member of staff to collect Jim in the morning. One member of staff would verbally reassure and encourage Jim while the other physically guided him out of the house, into the wheelchair then the taxi. This worked well. The situation settled again with only one member of staff if required. However, the option of extra support is there, providing Anna with reassurance.

REVIEW	
Personal outcome: social contact	*Personal outcome: social contact*
Jim	Anna
Jim is able to continue to attend the day service, where he enjoys the company	Through Jim attending the day service, Anna can spend time maintaining relationships with her grandchildren
Personal outcome: wellbeing	*Personal outcome: wellbeing*
Although Jim's mobility has shown signs of deterioration recently, he retained motivation to walk and his mobility was maintained through being supported to walk out of the house into the bus	Anna is able to continue to enjoy leisure time to herself which reduces her stress and improves her wellbeing
Personal outcome: being listened to	*Personal outcome: being listened to*
Jim responds well to the verbal and physical reassurance he gets from staff when his mobility is poor, which he shows by nodding and winking	Anna was really pleased that the social worker had listened to her concerns about the stairmatic and 'provided a lifeline' by coming up with an innovative solution
How achieved	How achieved
A stairmatic was proposed initially but was not suitable. Instead an extra member of staff safely guides Jim out of the house if required	Anna did not want a stairmatic in her house as this would have cluttered up their limited space. Instead, an extra member of staff is available to safely guide Jim out of the house if required

3) David and Meg

In this story the outcomes are identified through a review. Different formats are used by different teams. This record includes space to identify how outcomes were achieved, including the role of staff.

David lives at home with his wife Meg. Meg has cared for David for several years, since his diagnosis with vascular dementia. Although they managed without support in the early stages, both David and Meg's quality of life decreased as the dementia progressed. David began using a wheelchair two years ago, and with his mental health declining, the couple found it increasingly difficult to maintain contact with the outside world. They were both experiencing mental ill health. David and Meg have been a couple who value their privacy. When Peter the CPN first met them they were keen to avoid service involvement. However, Peter maintained contact and over time, the couple developed trust in him. Two years ago, they decided to accept the involvement of Alzheimer's Scotland. Peter also arranged to have a ramp attached to the house and for Meg to have a mobility car. These supports have had significant impact. David, who had given up hope of enjoying life, now gets out and about four times a week, enjoys the relationships he has built with the workers and has taken up fishing for the first time in years. David is much less depressed. Meg has been able to get back to bingo with her friends, which helps reduce her stress, and she enjoys going shopping on her own, knowing that David is happy with the support workers. Meg says she has never looked back since the support started. She reports that their relationship as a couple is much more positive.

REVIEW	
Personal outcome: Seeing people	
David	Meg
David has enjoyed building new relationships with his support workers	Meg has **reconnected with friends** through having time of her own
Personal outcome: being as well as you can	
David is more relaxed with Meg now that they are not together all of the time and he is appears less depressed, more affectionate and more responsive	Meg feels that due to her lower stress levels and his reduced depression her relationship with her husband has improved
How achieved	
Although David's overall health is gradually deteriorating, his welbeing and mood have improved in some respects, as noted by Meg, the CPN and support staff. Meg reported that this was achieved through efforts to 'listen to' what matters to David, and finding good support workers.	Meg repots that she is delighted to have 'time to herself' to help manage her stress. Meg's only regret is that they didn't accept help sooner. Being able to trust the CPN and support staff to listen to her and 'understand her worries' has been critical. Meg was delighted with the mobility car. Along with the ramp and support workers this has opened the possibility for them both to 'have a life again.'

4) John

This example from a social work team leader provides a detailed story about a man who was supported to remain at home despite increasing concerns about risks and the additional complications brought by other health conditions. The record takes the form of a review of outcomes.

John was in his late 70s. He had been diagnosed with dementia 2 or 3 years before. He lived at home and was very independently minded. After experiencing renal failure, John had a lengthy period of hospitalisation, and had a traumatic loss of memory, losing 30 years' memory of his life. John moved to a care home for a period of assessment before returning home. The family were anxious about how John would manage. The main carers were the granddaughter and her husband, who had just become parents. Initially, John returned home for day visits. He recognized his home, and was determined to continue to live there, threatening to kill himself if admitted to a care home. Advocacy was involved prior to John returning home.

John was a roofer in his younger years. As his dementia progressed, and following his sudden memory loss, he thought he was still working. This presented significant risks as John also had a tremor from Parkinsons. John

wanted to get up on the roof to work, so all ladders were removed. He was then discovered trying to use the ironing board as means of climbing up to replace a light bulb. He also repeatedly tried to access the garden shed, which was full of tools, including power tools. The shed was kept locked up, which frustrated John to the point that he smashed the windows at one stage, to gain access.

When John first returned home he had intensive support, while the assessment continued to ascertain what support was required for him to be reasonably safe. It was decided that John didn't require overnights. However, multi-disciplinary support was required, given his health needs, and a joint risk assessment was undertaken, reaching a shared decision that risks should be managed at home.

The practitioner successfully applied for a budget to provide support. Assistive living technology was also used, with the granddaughter acting as responder. Although John was not a great mixer, he was content enough to attend the day service a couple of days a week, where his health needs could be quickly responded to. A private home care provider was engaged, and they identified a small group of staff who worked consistently with John, to provide continuity of care. They reported that if he got fed up, he would leave the house. The workers would watch from a safe distance, and found that he never went far, and would return home of his own volition after a short time. After a while, John was not well enough to attend the integrated day service, and their outreach service visited at home instead.

The family worked closely with services, and there was discussion about how to include John in activities, to distract him when he became agitated and to avoid him feeling he had been put aside. John liked to move furniture, so they would try to ensure that any tasks requiring items to be moved were allocated to him. The riskier tools were removed from the shed, allowing him access again. After John had been back home for several months, he had a recurrence of cancer, with a very limited prognosis. He was supported to stay at home until the end of his life, when he was admitted to hospital, with his family remaining in close contact.

REVIEW
Personal outcome: Living where you want
John was able to return to live in his own home, which was critically important to him, and was associated with threats of ending his life, after hospitalization. Following John's recurrence of cancer he continued to be supported at home, only admitted to hospital in the last days of his life
How achieved
John was returned home with a package of support, obtained through SDS, to enable in depth assessment of his health and ability to manage
Personal outcome: Meaningful activities
Due to traumatic memory loss, John believed that he was still a roofer and wanted to engage in activities which relate to his previous job, which were high risk given his health conditions. His behavior consistently showed that he wanted to still feel that he was useful by undertaking tasks
How achieved
A joint risk assessment was undertaken. John was then supported to engage in

activities which are less risky, such as using tools and moving small items of furniture, while avoiding more risky activities such as going on the roof and using power tools. His family worked with services to enable this to happen
Personal outcome: Getting out and about
John wanted to get out of the house if he got agitated, and did not want to be pursued
How achieved
Home care staff watched John to make sure he was safe, knowing that he would shortly return to the house in a less agitated state
Personal outcome: Being as well as you can
John did not retain information about his health conditions. His family and staff were keen to ensure that he was supported to be as well as he could be, given his dementia and Parkinsons
How achieved
John had access to health monitoring and care via the day service, which meant any changes could be quickly responded to

5) Tony and Susan

The final example is from a social worker, who worked with a family where early onset dementia was affecting both parents and the teenage daughter. The review identified a range of outcomes, with a selection included here.

Tony is 52 and is married to Susan. They have a 14 year old daughter, Keira. Tony was a qualified electrician and Susan was a nursing assistant. Tony has not worked since he retired due to ill health in 2005, following a stroke. Susan had to give up work to look after him. Due to loss of income the family had to sell their house, obtaining a council house instead. Tony was later diagnosed with C.A.D.I.S.I.L., a neurological condition causing vascular dementia. In the past couple of years Tony's support needs increased and the family have had more contact with services, including the DPC becoming involved in recent months.

Susan asked for a carer's assessment in Spring 2014 because Tony couldn't be left alone due to leaving the house and then not knowing where he was. The DPC completed a community care and carer assessment. Tony's condition was deteriorating rapidly. Susan was struggling and worried that Keira was too embarrassed to bring friends home from school. The couple were very quiet at first, but opened up as the DPC got to know them.

There are other family members involved. The family had been on holiday with relatives in the Summer and really enjoyed it. As Tony's condition has deteriorated, Susan has said how much she misses her husband. The DPC supported her in coming to terms with the changes while recognizing that some aspects of Tony's personality are intact.

There was a further deterioration in the last few months. A review in August, involving the family and professionals, exposed gaps in support, especially for the carer who was very tearful and expressing worry about her own wellbeing.

Tony has limited awareness of the impact of his condition on his wife. Susan needed a break, but there is only one registered home for people under 65 in NL. Given Tony's age, the co-ordinator asked locality support to get involved. The worker David spent time getting to know the family, adding to the DPC assessment by exploring their outcomes. Tony is now supported to access the community three days a week. It emerged that he was a great music fan and played the guitar. He was supported to attend gigs include Big Country.

More recently Susan requested support for Tony to allow her to go away overnight with her sisters. Tony, with his interest in music, wanted to go to Liverpool for a Beatles weekend. Initially, the DPC got tied in knots to access funding for this. Tony does not have SDS yet but the DPC secured funding through the respite budget and the trip to Liverpool is going ahead, with *All Together Travel.* The support worker from there has met Tony a couple of times and is organizing the two-night trip. Tony is really looking forward to the Beatles experience and Susan to her break with her sisters, using the additional time to do a bit of Xmas shopping and have lunch out with Keira.

Personal outcome: meaningful activity	
Tony	Susan
Tony is able to maintain community connections and continue to pursue his love of music	Susan has time to spend on her own, and time with her daughter after school, while Tony is supported to access community connections
Personal outcome: Seeing people	
Tony is keen to maintain contact with support staff who share his love of music and is really looking forward to the planned trip with Graham who he describes as 'one of the good guys'	Susan is able to spend time alone with her sisters, and to spend time with her daughter, doing things that they both enjoy.
Personal outcome: Positive family relationships	
Tony appears to be more animated in general and Susan reports that he is happier in her company since he has a life of his own	Susan reports that her relationship with her husband is much better since his mood has improved and she's getting time to herself too. She noted that Keira's mood has improved a bit and that Keira is confiding in a trusted neigbour
How achieved	How achieved
Following assessment by locality support, Tony has support to access community connections relevant to his interests	Following assessment by locality support, Tony has support to access community connections relevant to his interests
After being very reticent to start with Tony is relaxed and responsive in the company of the DPC	Susan has commented how important it is to her and Tony to have someone they can 'trust to listen' in the DPC