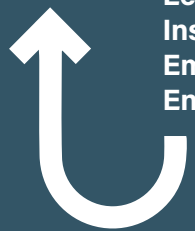


# Magic moments in dementia care services

A storytelling approach to  
learning and development



Learn  
Inspire  
Empower  
Enable



# Foreword

As Chair of the 3 Nations Dementia Working Group, I have played a role in helping deliver a series of webinars some around the impact of COVID 19 on people affected by Dementia. As well as being united against dementia we now find ourselves united against COVID 19 as well, which has had a major effect on people living with dementia and their carers. We must learn from the experiences, with health and care workers and third sector organisations continuing to play an especially important role in supporting and protecting the rights of people living with dementia during the crisis in the UK. Today learning from these stories to improve dementia care is more important than ever.

It has been my pleasure to witness people with a diagnosis and their supporters overcome doubt, lack of experience and confidence to tell their stories that have changed hearts and minds with content that cannot be questioned, or motives doubted as the testimony in this document illustrates .

No one who reads these stories will not be affected by the purity and bravery of the contributors all affected by Dementia. The people who delivered these moments were more concerned with their purpose than their own comfort.

We witness in this document extraordinary examples of courage, people speaking for the first time wracked by anxiety and self-doubt but doing it anyway, refusing to be defined by their diagnosis, demanding a place where decisions are made and sharing the most difficult aspects of their lives enabling a better understanding of the impact of a diagnosis.

So, we should salute all whose voices are heard and those who will be heard in future, those who battle daily, the changes a diagnosis can have. Let's celebrate for everybody is beyond brave in their own way our loved ones, friends advocate and allies.

Not all superheroes wear capes not all warriors carry armour.

Courage doesn't always roar. sometimes courage is that small voice at the end of the day that says;

*"You know what I will try that again tomorrow, I will be heard "*

**Nigel Hullah**

**3 Nations Dementia Working Group**

## Older Persons Commissioner

All professionals working across health and care services should understand the challenges people living with dementia can face, and the positive difference they can make by providing the right support and creating Magic Moments.

We've seen the huge difference that moments of kindness have made to people's lives throughout the pandemic, and this is something we need to hold onto and build upon as we move forward together.

I would like to thank all of the people living with dementia who overcame doubt, inexperience and a lack of confidence to make their voices heard and share their experiences so generously to create this valuable resource.

As you will see, their stories are both powerful and moving, and highlight why kindness, empathy and compassion are so important in the delivery of truly person-centred care, the kind of care that we would all hope to receive should we need it.

**Heléna Herklots CBE**

**Older People's Commissioner for Wales**



# Welcome

## Why should we collect and talk about stories?

Human beings are storytelling animals who make sense of the world through narrative<sup>1</sup>. They also **learn most effectively when they talk together and learn together**<sup>2</sup>, rather than passively watching PowerPoint presentations or reading strategies. In developing a set of national standards for dementia care services, we therefore wanted to take a **co-production approach that values and learns from the real life experiences of people**, rather than imposing standards that do not necessarily connect with the reality of everyday lives<sup>3</sup>.

This 'Magic Moments in Dementia Care Services' booklet has been inspired by the Developing Evidence Enriched Practice (DEEP) programme, a co-production approach to learning and development that was developed by the Wales School of Social Care Research<sup>4</sup>. The DEEP approach has demonstrated that learning through talking together about people's stories, both good ('magic') and not so good ('tragic') is powerful in effecting positive change.



Using the DEEP approach, Public Health Wales, Improvement Cymru brought together people with dementia, family carers, practitioners, managers and researchers, to share and talk about 'magic moment' and 'tragic moment' stories from their experiences of dementia care services. We achieved this through a series of regional events and associated meetings with stakeholders throughout 2018/19. As a result, we discovered **what matters most to people both delivering and receiving dementia care**.

This engagement has helped shape the development of an all Wales Dementia Care Pathway of Standards for the person's journey. The pathway has been structured around four key quality themes highlighted as important to people. These themes include accessible, responsive, journey, partnerships and relationships. Compassion and kindness were identified as critical attributes central to the underpinning of the four quality themes.





# Quality Themes

**Accessible** – able to get help, support and advice when needed

**Responsive** – meeting my needs at the right time, in the right way

**Journey** – navigating to the right support / service at the right time

**Partnerships and Relationships** – working together to achieve the best outcomes.

Underpinning the four quality themes is ***KINDNESS*** – *how we care for each other, speak to one another, engage with each other, work with each other, comfort each other and support each other.*

The pathway of standards reflects the spirit of the Dementia Action Plan 2018 – 2022) where the focus is on the person with dementia living a full, active life and promotes independence, coproduction and integration of services to meet each individual's needs. The standards also align to the following Dementia Action Alliance dementia statements:

- We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.

- We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.
- Our service and community response needs to be equitable – whether you live in a rural or remote area or in a town, and it needs to meet diverse needs, for instance people with protected characteristics who may be living with dementia and people who may be able to understand only their first language as their condition progresses.



The stories are supported by learning exercises to enable people to use the stories in this booklet or capture and learn from new stories. The exercises explain how to deliver exploratory talk activities with the aim of having a conversation about dementia, shaping practice and creating change ideas that will result in continuous improvements in dementia care.

By sharing the stories and key messages we hope to illustrate why it is so important that we build on the capacity to continue to share significant experiences about services, both 'magic' and 'tragic' moments. Working in partnership, talking, listening and understanding, will enable us to learn, grow and be inspired to continuously improve, to shape our dementia care services together in a way that matches our community's needs.

# The Stories

## Lean on me

**The community working together to support groups, places and organisations to be dementia friendly and accessible**

"Brian was asked to do a talk for an organisation in Wales and he couldn't do it. He was asked if he could recommend someone and we recommended an 86 year old lady who in her former life was a model, very tall and from Ireland. We went over to Ireland to one of the conferences and she came. We asked her if she would speak around the communities and we got her life story written down, who she was and she had an amazing story. Then we padded it out into the dementia friendly communities stuff. I went along with her and I said 'It is alright, I will be with you. I will stand alongside you and if you can't do it, it is okay. If you can't do it, you can just try.' So we stood on the stage and she started to speak and very hesitantly, she found her feet, held the audience in the palm of her hands. I stepped back, stepped back, stepped back and she had such an amazing

experience and she was also asked to speak with the same organisation in Wales again. She went there and this time, I drove her there and stood by the side of the stage. Again, she held the audience in her hands. The story behind this lady is that she had her diagnosis with dementia and she is a member of the women's church group and she brought the subject to the group and they said 'We would rather you didn't speak about that.' The lady said 'I have been speaking about it in another town.' The group members asked 'What have you been speaking about?'; 'Well, I have speaking about dementia and dementia through the community.' The group asked 'Would you give us the talk?' The group that had made her feel very uncomfortable for having a diagnosis, actually wanting something that she had to offer, she became part of the group again. She raised their stigma and then was asked to speak at lots of other church groups within her area, so while we supported her for the first two gigs, after that, she was on her own and out within the community and changing other people's lives. That to me was massive".



## Language matters

**Making reasonable adjustments so that the person is able to participate in their life**

"When I spoke French to a lady who was being nursed in bed and her face lit up and she replied in French. From there her care included a French speaker".



## Keeping me 'me'

**Understanding people, where they are now and enabling them to feel comfortable with who they are**

"My story was regarding a friend who transitioned and then got dementia. Their partner supported them, but because they had forgotten where they were, they sometimes regressed to an earlier time and we were concerned that they couldn't be themselves. Sometimes they were okay, sometimes they weren't. The solution was every day the person's partner made out two sets of clothes and they wore whichever they were comfortable wearing and if it changed during the day, it didn't matter if they wouldn't change, they supported whoever they were. I wrote that out with some work that we did, saying - would I feel comfortable if I had done an advanced directive saying I must be treated as a woman and then if I could be that in my future I might be questioning myself, why didn't someone determine this for me?"

# The Stories

## I wanna hold your hand

**And when I touch you, I feel happy inside, It's such a feeling that my love, I can't hide, I can't hide**

I have always visited my husband mostly everyday and I would visit for anything between 2-4hrs and was able to feel that I still had a role to play in his care. He would always eat well with me, where sometimes he wouldn't with the ward staff and staff also observed that his most settled part of the day was during my visits.

The sudden introduction of the Covid19 no visiting policy had a negative impact on us both, particularly as he had no understanding of why I wasn't able to visit. Despite trying to maintain daily contact via video-calling, facilitated by the OT and the nursing staff, it proved to be very difficult. The nature of the dementia meant he was often unable to comprehend what we were trying to achieve, which was very distressing for me. Sensory factors, especially touch, like holding hands,

hugging, massaging of his hands and feet had been an important element of our visits and brought us great comfort and this was now gone. My husband lost more weight and deteriorated further while I was unable to visit.

When the amended guidance was issued for inpatient visiting, the ward team and senior nurse were instrumental in setting up safe visits, recognising the positive impact this would have for us both. My initial visit after not seeing him for over a month was a real rollercoaster. On the one hand I was so relieved at last to be able to see and hold him again, but the realisation of how much he had progressed over that time was a great shock. However, even from the first visit it was clear to see how my physical presence and touch was reassuring again for him.

The ongoing empathy, compassion and support from the whole team, in continuing to facilitate the visits during this very difficult time, has eased my distress and also I believe some of my husband's distress. Please pass on my thanks to the whole team for their care and support and in continuing to recognise what an important role my visiting has as part of his ongoing care.





## You can do it!

**Enabling by matching the person's skills and abilities to the demands of the task**

"I work as part of the dementia team in a nursing home and I have been working with a lady that as a child, registered deaf as a result of meningitis and she had had a stroke or CVA which left her immobile, bed-bound; she's got no communication and she has been diagnosed with dementia. She gets assisted when she's fed and with my observation she gets very agitated when she's being fed and she's got no control over the task. I recently went to dementia training and occupational therapists were demonstrating the hand-to-hand feeding technique, so I couldn't wait to go into work the next day just to see if I could work with this lady to make this process a little bit more positive for her. I wanted to see how much function she had in the hand and the elbow to see if I could get a range of movement; I said I could do this with her, unfortunately it was very difficult for me to communicate with her because I don't sign, but she does manage to lip-read on small sentences.

I started doing the hand-to-mouth and she engaged with me straight away; it was mind-blowing, I thought it was amazing and she was in control, she was holding me back when she wasn't ready for the next mouthful, it was a magic moment and I cried when I got home because I

thought it was such a wonderful thing. A lot of the staff when she is eating, see that she shouts and she looks really annoyed, her facial expressions are normally, that she looks annoyed. But throughout when I was doing this technique she didn't, she was just quiet, she was content, she was in control, she was happy. So for me it was a magic moment and a lot of the staff noticed: look how quiet and look how content she looks and she's engaging with you with her eyes, her eyes lit up, it was wonderful.

On the downside of things, a carer walked past me and said, "That's a one-trick pony". Also, another carer walked past me and went, "We haven't got time for that" - I was on cloud nine, then I got hit with the negativity. So the next day I went in and I did exactly the same thing again and the patient responded to me like she did the day before and it didn't take that much longer, so all it means is that this lady has got control of what she's doing. It was just lovely for her to feel that she's doing something and I had a lovely smile out of her at the end of the activity, she wasn't flustered and if you can take that away its good, so my end result is that I'm going to try and train the staff with all their patients - so that's my magic moment".

## Creative ways

However professionally experienced we think we are, people are still more capable than we realise



"My story is a bit, old, but it's something that's stayed with me for a long time. A couple of jobs ago I was working as a liaison nurse in a care home. I was visiting somebody sitting beside this lady and I was aware of another lady the other side of her and her daughter sitting with her and the lady that she was visiting was very quiet, very frail and her daughter got out her iPad and started tapping away at it. I thought she's obviously a bit bored, she's just answering some emails, doing some social media whilst her mum isn't speaking, but no and what I like about this story and why it stayed with me, it proved me wrong and it made me think differently. Her daughter got up the piano app on her iPad and started playing and then she handed the pad to her mother and her mother started playing as well. That has stayed with me because it's proved me wrong and I just hope that it's always taught me that you shouldn't judge people however professionally experienced we think we are, people are still more capable than we realise and people can always prove you wrong and that's what I like".

## "I've still got something to give"

**The importance of people being able to participate in purposeful roles**

"Attending the Men's Shed enabled me to make decorations for Christmas, also taking over the coffee morning in chapel on a monthly basis and being able to collect money for the Alzheimer's has been a magic moment for me".



# Simply delicious!

***Empowering independence through meaningful everyday activities***

"Working alongside a young lady who'd been diagnosed with Alzheimer's for a six-week period. She'd previously enjoyed cooking for her family but had stopped doing so as was unable to follow complex recipes. We worked jointly to find less-complex recipes for her favourite things to cook. Working alongside staff daily, her abilities and confidence improved, resulting in her undertaking adapted tasks that she was able to do prior to her diagnosis. On leaving our service she independently cooked meals for her family and was supported by occupational therapists in the community team".

## A toast to life history

***Understanding the person to understand what might help***

"I work with people with advanced stages of dementia on the mental health wards. There was a lady on the ward. She was a diplomat's wife, so she's been everywhere, all round the world and she's come from a very highly sophisticated background. We were having trouble trying to get her to drink fluids. So, I thought - I'll try her with fluids in a wine glass and see how she

does. When she saw the wine glass she said, "Oh, thank you." Picked the wine glass up, with the 'pinky' up as well and drank. That was a good moment".

## The sun doesn't always shine on TV

***Ensuring we have established multi-disciplinary teams to provide a holistic assessment with access to range of interventions***

"I was visiting a lady in a nursing home who was referred for a communication assessment because she was hearing voices and hallucinating and had challenging behaviour. On visiting the lady, I noticed she was sat by a large television that was constantly on. Switching off the television the voices stopped and the lady became calmer. After speaking to the nurses and psychiatrists her medications were reviewed. Anti-psychotic medication was stopped and the lady became a lot calmer and communication improved".



## "Helping my spirit sing"

***The importance of finding the key to unlock the magic moment***

"Thursday is my magic moment because people will come in, being 'down in the dumps' and after twenty minutes singing and dancing, everybody is having a magic moment. A gentleman, who loved his wife to bits, who couldn't walk, said after the session to me, that he actually got his wife back".



## Pride before prejudice

***Identify people's strengths and interests to enable them to participate in activities that are meaningful***

"A 96 year old lady came in for an assessment with her son and daughter in law. Through the assessment, she didn't mention art at all, but it was only after when I gave her feedback about how she had performed and I had said how well she had done on the visual spatial test and the box was the best box I had ever seen. I said "Wow your visual spatial is excellent, you did really well on that" and her son then said "Well, actually she used to do a lot of art, although hasn't done for a couple of years now, but that is something she used to really enjoy." I asked "Well why, what happened, why did it stop?" and he couldn't really remember why it had stopped or what had happened for it to stop, so they said maybe we will get a sketch pad and some pencils and go back to that which was really good. I'm hoping to see some art work when I next see her"



# Understand what really matters

## Providing the right advice and support at the right time

"We think this story may be tragic and perhaps magic. We were called out suddenly to see a chap who was having problems with his wife, who had been diagnosed with dementia and she had been very confused a couple of days previously. She didn't recognise her own home and some other issues, so I went out to see them and he was very resistive to any care that had been offered. She had a UTI, which at that time had not been diagnosed, but we had a feeling that that was the issue. He was very, very

resistive to any input really from any care. He was offered a carer assessment – he didn't want anyone in there, he didn't want anyone involved and just through talking with him, initially I thought why was this guy so resistant. In some respect, he didn't want any GPs to take over the house because of other issues and he was getting quite tearful, but I was looking through what he was saying to me and recognising what he was saying... he was afraid of losing his soulmate and that was his main issue. People were talking it over

about whether or not he was doing the right thing for his wife about someone coming in and assessing. When it was explained that people were talking about how to keep his wife at home and that is what everyone else wanted. They wanted her to stay in her home, in a place that she recognised and be cared for as well as possible at home, he started to accept help to keep his wife at home, so that is the magic"



## A helpful starting place

### ***The Importance of a timely dementia diagnosis to ensure that life is lived well***

"I was speaking with a relative who rang to advise that their father had passed away. They were calling to thank me and the team for the support and for providing a diagnosis. By providing the diagnosis, the family were able to take control of the illness and were determined to make memories, especially around what was relevant to their father by revisiting places of interest, storytelling, something they probably would not have done. A powerful conversation where they highlighted the positives as opposed to the negative impact of a diagnosis"

# “Don’t judge me, just love me”

Supporting people to get the right support and care to enable them on their journey

“I was going to see patients with an acute clinical need within the community and I met a gentleman there that was needing the clinical care side of things and his wife was with him. When I first met his wife, she used to come and sit in the living room and sit very quietly. I’d get on with my job and I used to visit this gentleman twice a day and I went back to the office and told them I had done my job, handed over and they said, “You’re going back there this afternoon.” They said, “I bet his wife is still in that blue dress though isn’t she?” So they didn’t laugh at her, but they didn’t really think about what they were saying or what they were seeing I don’t think. So when I went back, indeed yes, the lady was still in a blue dress, still sat there and I took the time to sit and look and observe and obviously make conversation with his wife while I was looking after the husband. I came to realise she was a school teacher, she was a music teacher, she was a very social person in her time, but is obviously not able to carry out these things any longer and I thought this isn’t right, this lady’s not making her choices as I believed that she would perhaps like to. They were a very educated family. The gentleman used

to go out and he was a speaker, public speaker, so I learnt a bit more and he told me that sometimes his wife got quite distressed, would get quite jumbled. It just happened to be over a holiday period, so I went back and forth to this house lots of times in one particular week.

So I went the next day and his wife was having a little bit of panic, she got quite anxious, she needed the toilet, couldn’t remember where it was. I said, “Don’t worry, I’m here, I’m a nurse, I can take her”. Took her to the toilet and the poor lady had four pairs of pants, four dirty pads and each pair of pants just layered on top of the other, very evident then her clothes were much too large for her. I had a good relationship with the husband, so I asked, “Do you need help? Can I help you? Can I refer your wife into some services to see if we can see what’s going on?” So that did happen. After I found out she was a teacher, I’d go and see to the husband and do crosswords at the same time and she would sound out, a very intelligent lady. As we said, it’s just because there’s a dementia, it’s not they’re not intelligent, their thinking is a little bit different, so we used to do crosswords together. I found

out she likes me to take her a doughnut, do the crossword with her. She liked the Royals so it was at the time of the Royal weddings, I took her the supplements, nothing much just out of the Sunday paper, she was so pleased. I eventually got an assessment for a memory clinic, or primary mental health services and was able to help Mr .....as well in that.

From recognising and referring on, the lady got the services that she needed and was able to carry on at home. She wasn’t able to go out anymore, it got a little bit too advanced for that, not with him anyway, but she did go for an ice-cream with her daughter once - had her hair cut, new clothes, I spoke to the daughter. She had got clothes that fitted instead of the big clothes on her, which was from a long

time ago. They were what she used to wear but things started to fit her so she looked smart. She became the lady that she deserved to be and her husband was able then to go out and carry on his things because we organised a sitter, so he had his social stuff addressed. So, my magic moment really is I think that, just by taking notice when I went into that house; not just of the service user that was on our caseload, we’re looking around and taking notice, making sure that his wife had what she needed, so together they had six good months before things got so bad that she had a fall and went into hospital. She’s so advanced now bless her, that she needs a placement rather than home. So my magic moment is really that I gave them six months of good quality time together and that’s my story.”



## Living a life

**Recognising and seeing a patient as a person**

"Whilst working on a dementia ward and in a day hospital, I spent time compiling a life history for each patient, with the co-operation of patients' families and carers. Photographs and a history of their childhood, schooling, work and family life as well as hobbies, likes and dislikes helped me and other staff to work with the patients using reminiscence, talking about their jobs and hobbies etc. Staff stated this changed their attitude to patients, reminding them that they had lives prior to dementia. Also patients were engaged in therapeutic activities often resulting in less use of medication for agitation and therapy could be tailored to their previous interest and skills, the pleasure was evident. Life history could be taken on hospital visits making staff aware of their likes and dislikes. This was prior to "this is me". Participants enjoyed building up the information talking about past events. Staff stated it changed their outlook on the person, reminding them that they were a person not a patient."

## Building confidence, nurturing happiness

**Enabling networks, connections and relationships**

"We set up a group called Cognitive Stimulation Therapy for people we visited who had a diagnosis of dementia. It ran over six to seven weeks and to see people who were nervous and quiet in the beginning and by the end of the group much more confident, smiling, laughing was great. My magic moment is that the people continued to meet up after the group had finished"



## 'The fundamental things apply, as time goes by'

**Actions, behaviours and relationships we have with people and how we deliver care will affect how we make people feel**

"When I went to visit a mum who is cared for by her daughter, I can remember going into the lounge area and mum was sitting on a lovely comfy chair in the corner, all the photos of the family were beside her on the mantelpiece and she had the sun coming in on her face. She was wrapped in some lovely blankets and she just looked so peaceful, calm and relaxed. We were talking and her daughter went up to her, held her face and said "can you remember who I am, do you know who I am" and the mum said **"I don't know who you are, but I know that you love me"** and I just remember being really touched at that time"

while he was in a residential care home, which was lovely in many ways in that I could visit him whenever I wanted and could walk the dogs. I had been down to South Wales with both of my dogs and one of them had tragically died and I came back with just Tumbles. Dad at this stage wasn't verbal, he was at quite a late stage of dementia and I went to see him, didn't think he would notice that I didn't have Gruff with me, but as usual Tumbles came down and laid his head on his feet and I chatted and he smiled which is what normally happens, but then after a while he looked down and Tumbles was a bit restless, twitching in his sleep. Dad looked down at him and said "Where is the other one?" I replied "Sadly dad, Gruff has died, there was an accident" and he looked sad and we were both sad together. The next thing he said "I think he's missing his brother" and it was very much about my Dad missing his brother. I don't think he ever spoke to me again after that, but there was just this one moment where he was just absolutely with me in the sadness of the dog and the sadness of him and his brother and it was just beautiful"

## Good grief

**The Importance of understanding people's relationships past and present and the feelings they have associated with the relationship**

"To understand this, you will need to know that my father is one of five siblings, he is the youngest and he is very close to his brother. His brother had died 15 years before my dad had dementia and for a



# Dementia is everyone's business

*Understand and really “get me” to support and enable me through my journey*

“It’s very difficult to say and to identify a magic moment because my life is full of them – coming here today is a magic moment, meeting like-minded people is a magic moment, but there are things that make you catch your breath sometimes which you haven’t taken into consideration prior to this realisation and it was that my dementia is shared by everybody, **everybody shares my dementia** - wherever I go, whatever I do, whoever I see, right now in this room, you’re all part of my dementia journey because **wherever I go dementia is with me**; I can’t leave it at home and I can’t pretend it’s not there, it’s there. I live alone and whenever I speak anywhere I’m always sometimes introduced as: Nigel, the man who lives alone with dementia. I wish, I wish. There’s about 10 or 15 people who keep me afloat and I was off to get drunk with a friend of mine, a taxi driver, Alan and he said, “I know more about dementia now than I ever have before”. I said, “You’ve learned to read have you?” He said, “No”. He said, “It’s watching you”. I said “What?” He said, “Because I know now that it’s not the big scary thing I thought it was”. I said, “I’m just one person,

I’m aware of that”

All of my friends who support me, many of them I’ve served with and I’m known as ‘the demantor’ and what they tend to do is they tend to tell me things I don’t do right rather than things that I deliberately do wrong. I was going to a meeting with the Welsh Government. I was with Chris and Jayne and I had a lift to the station off Alan and I had a lovely 3-piece suit on but I forgot to put a shirt and tie on. But you see the reason I’m comfortable with this and I think it’s a metaphor for the way services should be provided; all these people know my history, they all know my preferences, they all know my ambitions and I’ve still got ambitions. They all know my weaknesses and my weaknesses are I guess my temper, I’ve got a terrible temper and if you want to be friends with me, that has to be taken into consideration. I think that should form the basis of a social care provision. It should be based on people who come into your room and come into your home and don’t say, “What would you like me to do?” They know what needs doing. They know how you want it done and they know who

should be doing it. I didn’t realise that my dementia is not unique to me because everywhere I go, people share it, Sharing my dementia, whether you like it or not, you are and it’s very important that we understand that it takes a while for people to get you to understand where you’re coming from and almost with dementia, when you meet somebody, it’s like having a girlfriend for the first time, you need to

know what makes them tick, what’s at the end of it and being in a support network is not easy because of the various things.

So my magic moment was **suddenly realising all the people that support me get me**, which I didn’t think before, I thought they were doing it out of friendship, loyalty and duty, but no, they get me”

## Everyone is an expert!

**Working in partnership to establish new ways of work to enable to support effective care and transition**

“Mum had been living independently, driving etc. A series of mini strokes left her very confused and lacking mental capacity to make decisions about where she would live. In hospital for six weeks and during this period I read up about dementia, including a book ‘Contented Dementia’. Towards her end of time in hospital, I mentioned to the Consultant

Psychiatrist that I wanted to implement a contented dementia plan for my mum. The Consultant showed interest in the method and offered to stay involved to help implement it. When the time came, he met with staff at the care home and with me to help implement the plan. The Consultant continues to be involved”

## Conflicting interests

Understanding people's relationships to support people through the journey

"Mine is a magic and a tragic moment. It is about two perspectives isn't it? I was asked to do a mental capacity assessment for someone within the team and it was around respite. I have met this gentleman a couple of times before and his wife and it was finding things that he liked to do. He had actually made his own furniture, for example, his coffee table, his TV stand etc. and it was fantastic work. There was a workshop at the back of the garden which he could no longer access because his wife didn't take him there so we explored getting a support worker to come in and get this hobby back. He was all for it and really engaged and positive, but for me the tragic thing was that his wife wouldn't allow him to do that, it was that barrier that it was too much work and she liked him to sit in his chair and be still and it was de-skilling. It was really sad. **We could do lots with this gentleman who still had the ability to do something that he enjoyed**".

## Time and attention

Understanding the person and their abilities to support and enable them to participate in valued activities

"When I was an occupational therapist in a memory clinic and often in the Valleys, we would get people who would come very late on in diagnosis and very often they are at crisis stages. We had a lady who had a dementia and her husband was caring for her. The lady was having difficulties with her self-care and the husband was finding this difficult to manage. The husband would lay out the clothes, she would get up and would sometimes wash and dress - if she did dress, she would stay in the same clothes. Her husband would say he wanted her to go into residential care. It took me quite a period of time to work out what the route of the problem was. Took me quite a few months and by the time I had finished working with this lady, I remember her dressed in all her beautiful clothes, as she was always a very well dressed woman and she would put her makeup and jewellery back on, she got to the bottom of the stairs and she had done a twirl and her husband said, "Wow, **thank you for bringing my wife back to me**" and after our input, she stayed at home for 18 months longer and that for me was my magic moment. It is part of us working together with dementia services and how they want to be".

## A major miner

Support and enable the people to meaningfully participate and engage in their communities

I am going to talk about someone you don't know. His name is Cliff, but he gave me a shining example of why **people with dementia cannot be ignored**.

We were part of a group who were looking at the feasibility of using a mine as a place for visiting, for people living with dementia. I happened to be there when Cliff was there. Cliff was from a nursing home and in a wheelchair - he had difficulties communicating. There were these wonderful curators that were ex colliers and I love talking to them because they have more stories than me!

They were showing us the safety lamps and Cliff was sat in his chair. All of a sudden, he jumped up and said "He's not doing it right" and he said again,



"No, he's not doing it right - I'm going to show you how it's done" and he got up and actually took the lamp from the tour guide, the care staff were amazed. He hadn't spoken for about two years. He hadn't communicated until he got out of his wheelchair and I asked, "Why don't you get a job here?" Charlie, the care home worker was next to me and she was in tears. She said "This makes it all worthwhile" and it does.

**Don't be surprised with what we can do, because we can do a lot.** Cliff, you're a hero. You'll never know it and never want to know it, he just did what came naturally by showing people the proper way to use a safety lamp. **He might have dementia, but he is also a proud old collier**".

# Using stories of experience to shape both service development, improvement and learning

The **stories** listed are full of meaning, as were the conversations we had about them. They **give us insight into what matters most in dementia care services** and point the way to the sort of standards we should be working to and give us food for thought for learning.

The stories, those 'magic moments' have also contributed to creating a coproduced set of standards for dementia care services and this booklet can be used to support implementation.

The stories in this booklet are supported by some **simple exercises** to help people talk about and learn from the 'magic moments.' **Stories can generate ideas for change – we call them change ideas** which can lead to improvement projects that are shared to spread the improvement across dementia care. It is important to encourage sharing and to **create your own 'magic moment' stories that can be used to learn, inspire, empower and enable others.**



## How to: Shape our Learning

Simple exercises for exploring and learning from stories

### It's good to talk

#### an introduction to Exploratory Talk

Reading these '**magic moments**' will invariably stir an emotional response. We are all touched by stories. However, **there is a danger that we are touched, but not moved to do anything different** as a result of this.

One of the best ways for stories to support learning and practice development is to share and explore them together, in small groups. This allows participants to think and talk about some of the values, ideas and issues that are contained within the stories. In so doing, participants begin to **shape and develop their own thinking** and the thinking of others. As a result, new ideas and possibilities emerge.

Lyn Dawes and Neil Mercer, University of Cambridge, have developed an approach

to facilitate these kinds of **conversations, called Exploratory Talk**, which has been used to support group learning with both adults and children.

This is a talk in which every member of the group is invited to contribute; reasons are asked for and given; contributions are treated with respect. A level of challenge is expected and ideas are chained together elaborated and explained as the discussion proceeds with the group aiming to reach a negotiated agreement.

Crucially, the group will encourage speculation and hypothesis. Discussion groups begin by agreeing on a set of 'Ground Rules for Talk' which will generate Exploratory Talk. The group takes responsibility for its discussion and no roles are allocated.



## Ground Rules for Exploratory Talk:

- Everyone will be asked to say what they think
- We will listen and think about all points of view
- Ideas will be challenged; reasons will be asked for and given
- We all share all relevant information
- We can ask for clarification, explanation, elaboration, or speculation
- We work towards a group understanding of each other's point of view.

By ensuring that the language of reasoned discussion is used, the group can expect to understand more about the topic or 'magic moment' and more about one another and can frankly share areas of uncertainty and lack of knowledge in a 'safe' forum. Some of the 'magic moments' in this book may appear risky to some and not to others. These different perceptions can be valuable in challenging assumptions and uncovering hidden issues that may need to be addressed.

## Exploratory Talk requires:

- A topic, which merits discussion. For example, 'magic moments' from this booklet
- Time in which to agree or generate Ground Rules for Talk
- Time for the discussion to unfold
- A clear use or purpose for the products of the discussion. For example, what are the implications of the 'magic moments' and our discussion on our practice?

The chance to hear and consider a range of points of view in equitable discussion is invaluable. In addition, such reasoned discussion enables participants to assimilate the tools of reasoning which benefit thinking when subsequently problem-solving alone.



## Exercise 1:

### Facilitating a simple Exploratory Talk discussion around 'magic moments':

**Possible context** – this exercise would be ideal in a practitioner team meeting, or a consultation exercise involving practitioners, family members and people with dementia

**Time needed** – this exercise requires 30 to 45 minutes

**Group size** – ideally around 15 - 20 people

**Setting** – a room with a circle of chairs and floor space so that people can walk around and spread out.

## Preparation

Select 8 to 10 'magic moment' stories from this booklet, or from your own practice. Using PowerPoint or Word, type each 'magic moment' on a separate A4 sheet with its title and ideally a creative common picture from the Internet that illustrates the 'magic moment' (see care home example below). Once completed, print off each illustrated 'magic moment' on a separate sheet of A4 paper.



## Until death us do part

A man in our service who lived with dementia asked me for a pencil and tape measure which he could see on the desk. I did not know why he wanted them, but gave them to him. From that day on he did not put them down. For a start, he used them to measure the floor with a big smile on his face as he did so. When his wife came to visit she commented that she had seen a big improvement in his mood, as he was constantly smiling and busy, measuring and recording information. This man had been an undertaker and that he was probably measuring us up for our coffins! This man had been an undertaker since he was 14 and this had been the family business for many generations. A small plastic tape measure and pencil had made all the difference to this man, through which we were able to support him in achieving a sense of familiarity, purpose and achievement.

## Facilitating the exercise provides the background

Start the exercise with everyone sat in a circle. Tell everyone about the importance of valuing stories from practice, e.g. 'magic moments' and how they can inspire us much more than bullet points on a PowerPoint presentation. You can also point out that people make sense of the world through stories and learn and grow through sharing and talking about stories with others. You might want to share the following **Terry Pratchett quote**:

*"People think that stories are shaped by people. In fact, it is the other way around"*

## Set the Ground Rules for Exploratory Talk

Discussion groups begin by agreeing on a set of 'Ground Rules for Talk' which will generate Exploratory Talk. The group takes responsibility for its discussion and no roles are allocated as in Reflective Exercise 1 established the ground rules.

## Instructions for the exercise

Tell participants that you are going to talk about 'magic moments' using an approach called Exploratory Talk.

Give them a short description of Exploratory Talk and ask them to identify some ground rules for talking together about the 'magic moment' stories.

Once these have been agreed, ask the group to listen carefully to each of the 'magic moments' in turn. Invite individual participants to read out loud one of the 'magic moment' stories in turn until all have been shared.

After they have all been read out, tell participants that you are going to place the 'magic moments' spaced out on the floor and invite them to stand by the 'magic moment' which seems the 'most magic' to them.

Invariably people will pick different 'magic moments' or the same 'magic moment' for different reasons. This is a rich source for learning. Once everyone has selected their story, invite them to start talking about why they have chosen this story, taking each selected 'magic moment' in turn. When discussing each story, you can tease out the conversations by asking a range of questions. For example:

- Why did you pick this story?
- What are the important values or themes within this story?
- Does anyone agree or disagree with this?
- Is anyone worried by this story? Were there any risks?
- Does anyone in the room have something else to say about this story?
- Does anyone have any similar or contrasting stories from their own practice?
- What are the implications of this story about the way we work?
- What are the implications of this story for our managers?
- Can anyone think how this story could lead to another, perhaps even more 'magic moment' stories?

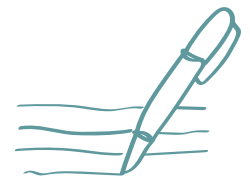
Whilst participants are talking, it is helpful to have someone writing down key points on a sheet of flipchart paper. For example, some of the following themes may come up: Relationships matter, people need meaning and purpose in their lives, a sense of belonging or continuity with past life etc.

Repeat this process for all the 'magic moment' stories.

At the end of the discussion ask everyone to sit back down in the circle of chairs and facilitate a general discussion about what has been shared, referring to the flipchart notes.

Once everyone has had their say, invite them in turn to share their 'last words' on the subject, ideally what they think could be done within the service or organisation that would support more 'magic moments' like the ones that have been discussed. It is important not to put pressure on people to say something if they do not want to. Give them the opportunity to say "pass" if they don't want to say anything.

Hopefully, by the end of the exercise, you should have a list of ideas for action and a group of inspired, better connected and encouraged people.



## Exercise 2:

### 'Magic moments' and Positive Risk-Taking, by Steve Morgan

Reading through the 'magic moments' outlined in this booklet reminds us that ***we are all a collection of our past joys, experiences and even challenges.***

They represent our way of searching for personal connection, meaning and identity. Each and every one of us is an individual and so are our magic moments; deeply personal experiences that bring a tear to the eye of the beholder and of anyone else that witnesses or reads about them.

In all of the stories, a consistent message is that someone took a risk in order for the 'magic moments' to emerge. It might be a risk about an activity, a risk regarding the nature of relationships, or a risk of failure in stepping outside the norm or pre-determined care plan. Positive risk-taking, in this context, is all about creating the experiences that produce that tear of joy, the passing smile, the kind word, a tiny act, a bold action, a big achievement, or a rekindled wish. Taking a risk is so important in all of our lives, so the question is how we can go about doing it with others who may be more vulnerable for reasons of health and personal circumstances. Often we ask ourselves and others "What is the risk of doing something?" In positive risk-taking, we have to ask a different question i.e. ***"what is the risk of NOT doing something?"***

Regulation, inspection, guidelines and protocols have a place, but that place is more commonly concerned with organising and managing services. In the case of ***'magic moments'***, if any attempt is made to over-analyse the moment the magic will be lost... ***you can't care plan for them to happen!***

So ***we need something very different if we are to create the conditions for magic to happen.*** We need to adopt a 'glass half full' approach by asking, ***"What is it we can do and how can we make it happen?"*** Just identifying the difficulties and how we should stop them simply doesn't work. The most important skills are those of every day courtesy and common sense, combined with a few 'magic moment' type of questions.

### Things to bear in mind:

- It's about our personal histories, so gently enquire about the past
- Listening to people
- Focus on them rather than make assumptions about them
- Use the person's own language, not the jargon of services
- What does risk and taking a risk mean for them?
- Being observant in order to see the smallest of reactions to personal reflections and experiences
- Taking action to support the moment to become a reality (or considering the rare occasion when it is a risk too far).

## Thinking about 'magic moments' in your own life and how to create them for others:

The following reflective questions can be explored individually or as a small group. Reflecting on your experience of 'magic moments' in your own life.

- What did you used to do?
- What did you enjoy the most?
- Where did you live?
- Who have you met and known?
- What was the smallest thing that gave you the most pleasure?
- What risks were associated with your own 'magic moments' and were they worth taking?

## Creating 'magic moments' for others:

- What is the potential 'magic moment'?
- Why will it be so positive for the individual?
- How can we make it happen?
- Who needs to be involved in making the decision?
- Who else needs to be informed?
- Who needs to do what?
- How will we know when it happens?

- When will we know it is too risky?
- What will we do to stop this activity if and when it is becoming too risky?

The answers to all of the above questions are not straightforward, but they are worthy of exploring if we are to nurture creative, kind and wise practice in dementia care services.

**In a world all too often dominated by fixed rules that demand compliance, we need practitioners who do the right thing for the right person, in the right way and at the right time.** This cannot be achieved by following rules. The American Psychologist, Barry Schwartz, suggests that the best health and social care workers are like jazz musicians.

***"Don't get me wrong. We need rules! Jazz musicians need some notes... but too many rules prevent accomplished jazz musicians from improvising, and as a result, they lose their gifts, or worse, they stop playing altogether!"***

Extract from TED talk available at: [www.ted.com/talks/barry\\_schwartz\\_our\\_loss\\_of\\_wisdom](http://www.ted.com/talks/barry_schwartz_our_loss_of_wisdom)

We hope that exploring these stories, standards and learning activities will promote the wise and virtuous practice that is necessary to make the spirit of the Dementia Action Plan 2018 – 2022 a living and vibrant reality.

\*\*Exercises adapted from the DEEP project, Swansea University'



# Digital Storytelling by Digital Communities Wales

Digital storytelling is a simple, creative process through which people with little or no experience in using online technology can tell a personal story as a short film using still images, narration and music.

Using simple and usually free apps, digital stories can be created with a smartphone or tablet. Digital engagement is crucial to the process of putting together a person's story so support for the individual telling the story may be required. Encouraging participants to reminisce and tell stories from their lives can have many positive health benefits and capture magic moments.

The following is from research undertaken by Innovation in Ageing in 2018:

"Digital storytelling benefits seniors as it promotes active reminiscing, and the direct participant involvement in the story creation on a digital platform. It also challenges the limitations of dementia, possibly creating new paths inside the brain or delaying the decay of existing ones."

"Themes in the stories include older adults' lives, experiences living with diseases, and factors that contribute to longevity. Positive changes in older adults are confidence, level of speech, sense of purpose and fellowship, social engagement, motivation and, intent to change one's health behaviour."

Digital Communities Wales (DCW) offers training sessions: for apps that are available on Apple devices and apps available on Android devices. During the session DCW will demonstrate how you may use these apps to upload images and combine them with a narrative or written text and music to create powerful short films for learning.



# Change ideas

Conversations and stories or any narrative is called qualitative data and is vital in the world of health and social care quality improvement. **Stories** support the numerical data, (quantitative data), as *it brings a reality to the numbers*. **Stories can paint a real picture about the experiences of people who receive care and the people that deliver care.**

By using this booklet we hope conversations will happen and stories will be captured that in turn produce ideas for change. **Stories** can be explored to help us understand the detail and **learn about what really matters**, what is really happening and what people are thinking and feeling. This process will help us focus on the ideas generated that can make a difference to the quality of care and supports a quality improvement approach that can be shared, resulting in a change; to the care practiced, to the environments of care and to new initiatives developed and adopted.

You can learn more about Quality Improvement in Wales by visiting Improvement Cymru's website.

## HOW TO: evidence learning from stories

When the stories and exercises in this booklet have been used to develop conversations and new stories about dementia care, and change ideas have been generated, we would like you to **share your stories and learning**.

A simple template has been developed by Improvement Cymru and practitioners engaged in the National Dementia Care Programme, to encourage reflection and learning. It is **important to capture how the stories and exercises have impacted on the knowledge and skills of the people that provide care which will result in a positive impact on the quality of life to the person living with dementia, families and carers**.

The learning template is available to download on the Improvement Cymru Website, <https://phw.nhs.wales/services-and-teams/improvement-cymru/> along with guidance on how we can share this work nationally as part of a learning from stories resource.

Improvement methodology includes asking the FIVE WHYS to get to the root cause of a problem, we have used a similar approach by using the FIVE Ws to focus on the learning and development that can shape the way dementia care is delivered.

## FIVE Ws – key questions to shape and evidence learning and development that can create Magic moments in dementia care

- **Tell your magic story**
- **Why** is your story **magic**
- **Who** is involved in your **magic** story - who are the people connected to your story and who has learnt the most - for example: you, your colleagues, family and carers, the wider community
- **Where** and **how** can you share this learning with other practitioners and carers - there can be many ways to use this learning in a variety of settings
- **When** and **how** will you use this learning opportunity to evidence a change in **your** practice?
- **What** difference has this **magic** story made to you as a person and to your practice?
- **What** difference has this learning opportunity made to people living with dementia and their carers and families?
- **What** other learning opportunities do you need to develop your practice and who you will discuss this with?



## Acknowledgements

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Additional drawings created by Primary School children in Cardiff.

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The DEEP Project:  
[www.walessscr.org/en/deep](http://www.walessscr.org/en/deep)

Improvement Cymru are the all-Wales Improvement service for NHS Wales. We are experts in developing, embedding, and delivering system-wide improvements across health and social care:  
[www.phw.nhs.wales/services-and-teams/improvement-cymru/](http://www.phw.nhs.wales/services-and-teams/improvement-cymru/)

Integrated Storytelling:  
[www.artsinhealth.wales/integrated-storytelling](http://www.artsinhealth.wales/integrated-storytelling)



The drawings in this booklet have been created by the children of Bishopston Primary School, Swansea, supported by the educational charity XLWales -

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