A Different Way of Knowing

Using Patient Stories as an Educational Resource

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About this Booklet

There are a great many ways that patient[1] stories can be used as an educational resource in the context of strengthening communications and human relationships. This booklet aims to provide a flavour of just a few of the approaches that can be used to make a point, stimulate individual reflection or seed group discussion on some of the more fundamental aspects such as:

- Developing special ways of listening
- Exploring incidents and encounters, both negative and positive
- Challenging assumptions
- Making sense of experience
- Gaining insights into the lived experience of others
- Exploring the diversity and complexity of relationships

The booklet can be worked through sequentially or used as a ‘dip in’ resource:

- To support exploration of a specific aspect of communication
- To reflect on particular incidents and events
- As part of scheduled teaching and training sessions
- In staff development work
- To promote discussion during staff meetings

Guiding Principles for Group Work Facilitators
Learning about communications and relationships cannot happen in isolation.

Listening to and engaging in dialogue with others is very much at the heart of this booklet and many of the featured exercises involve small group discussions.

All group work is guided by the following principles:

- Establish a safe environment for listening to and sharing stories
- Keep sessions loosely structured – put your trust in the process
- Ambiguity is tolerated within stories and within the responses they elicit
- There are no right answers to the questions posed in this booklet
- Multiple perspectives are welcomed and enrich the learning process
- People value their own conclusions more than yours! Give them time and space to reach them
- Explore a mixture of positive and negative issues and encounters, but always leave participants with hope.

[1] Here the term “patient” is used to refer to people who use care services, their family members and other supporters.

Making the Case for Stories as an Educational Resource

Stories have been used for centuries as a valuable means of communicating a special kind of knowledge.

With the increase in scientific knowledge in recent decades, stories were somewhat overlooked as an educational resource.

This situation however is beginning to change.

Uncovering Lost Meanings

"With the increasing complexity of health care, I felt the need to 'cover' more and more content. Yet it seemed that I had less and less time to help students to understand and apply this content. With the focus on *covering* content, I seemed to be covering over, or obscuring the important meanings that I wanted the students to grasp. How could I uncover these meanings for students? Using stories in my teaching has provided this answer".

Sorrell (2000)

Developing Understanding

Developing better communications and human relationships requires a better understanding of what is involved in these diverse and often complex processes. Stories are integral to the way we communicate and make sense of experience. Reading, listening to, reflecting upon and discussing the stories of not only patients, but also those of their supporters and staff at all levels are all essential in developing this understanding.

Discovering a Different Way of Knowing

Telling someone a story is quite different from teaching them the facts. Story is less direct; it gives people space to think for themselves and find their own meanings. Telling a story is a bit like sowing seeds. Some seeds will land on stony ground, but others will take root, develop and grow in the mind of the listener.

Stories can also engage people at an emotional level and unlike bullet points or lists of values, stories are memorable. A story cannot tell someone what to do, but it can exert a powerful influence over what they think about as they make their own choices.

"What the heart understands today, the head understands tomorrow"

Anon

Once Upon a Time…..
Story Types, Story Places

Overview
The following introductory exercises aim to get people thinking about:
- The different types of patient story that we can learn from
- Different beliefs about what counts as evidence
- Where and how patient stories are shared
- What helps and hinders learning from story

The stories recalled by the participants are not shared during these introductory exercises. They can however be gathered up at the end and used as inputs to some of the subsequent group exercises, subject to participant agreement.

Focusing and Reflecting Exercise
Answers on a Postcard

Each participant is given a blank 4 x 6 postcard

Can you think about a time when hearing or reading a patient story influenced the way that you communicate with or relate to others?

Take a couple of minutes to think of a story.

Take 5 minutes to:
- Write a summary of the story on the front of the card provided
- On the back of the card, write a short description about the way in which it influenced you

Facilitator Notes:

If anyone is unable to think of a time when a patient story influenced them in this way, they can instead identify a personal encounter that could be told as a story, if necessary taken from everyday life rather than the care context.

Telling a story is very often the best way to get people to think of a story. However, try not to use a 'stimulus story' here, as this tends to influence the type of story that people recall.

Don't worry if people are unable to think of a story; this can inform the discussion.

Exercise: Types of Learning Stories

Find out:

- How many people recalled a negative incident story? - A ‘never again’ or ‘I don’t want to do that, or be like that’ type of story

- How many people recalled a positive incident story? - A ‘yes, I want to do that or be like that’ type of story

- How many recalled a neutral or insight story? - A story that offered an insight into someone else’s experience that made you think or act differently, or a story that caused you to challenge a previous assumption

- How many people recalled a ‘mixed story’? - A story containing effective and ineffective moments within the same encounter or relationship

- Did anyone recall a story that didn’t fit under any of these categories? If so, how would they define it?

- How many people were unable to recall a story?

Write the number of stories recalled under each story type on a flipchart.

Group Discussion
What does this tell us?

For each identified story type in turn:
- What sort of influence did the story have on you? E.g. Immediate or delayed impact on your understanding, thinking, attitudes, behaviour or practice
- What do you think about the value of the different types of story?
- What are the potential dangers of being influenced by a single story?
- What sort of steps might be taken to check out the relevance of the ‘take home’ message in the local care context?

Discussion Points
The discussion will very much depend upon mix of different types of story recalled by the participants. For instance, often people will be predisposed towards thinking about learning from what went wrong and will recall negative stories. In such cases it may be useful to begin to think about other story types, particularly positive reflections. If however a mix of story types is identified, this can open up discussion about the value of different story types, and also establishes the value of different perspectives.

The discussion can also begin to identify different people’s beliefs about the role of story as a tool of influence, what counts as evidence and the fit with the local care context and culture.

Exercise: Where and How Stories are Shared

This Exercise builds upon the previous exercise[2] or can be conducted independently using the previous *Answers on a Postcard* prompt.

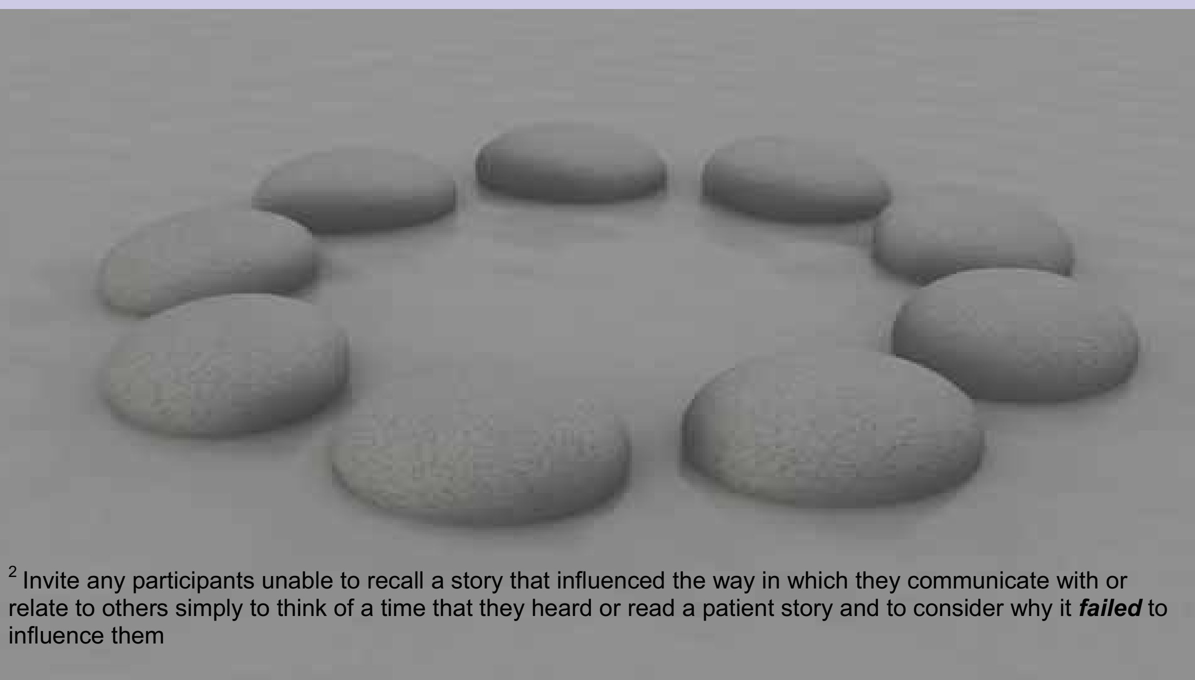
Group Discussion
How did you hear the story? Where were you?
E.g. In the work place, as part of a training course or self- discovery via the web, a book etc?

What was it about this particular story that influenced you?
E.g. The story itself, the way the story was told, the clarity of the point made, its emotional content, its relevance (to the topic being discussed and / or your personal experience) its explanatory value, an element of surprise?

Was there an opportunity to reflect individually on the story?
Was there an opportunity to discuss the story with others?

> If so, what did you learn from this?
> If not, do you think it would have been helpful or unhelpful? Under what circumstances?

Discussion Points
The discussion will very much depend upon mix of learning contexts identified. Some participants may identify the importance of a well told story and its immediate emotional impact, others may identify having time and space alone to engage in highly personal tasks such as examining their own attitudes and assumptions, whereas others still may welcome the opportunity to engage in dialogue not only with the self, but in a group. This serves to get to know the make-up of the group, to establish the different ways that the patient story can be used as an effective educational resource and the factors that different people identify as helping or hindering the learning process.



[2] Invite any participants unable to recall a story that influenced the way in which they communicate with or relate to others simply to think of a time that they heard or read a patient story and to consider why it ***failed*** to influence them

The Other Side of Language
Different Ways of Listening

Patient stories can be used to good effect to encourage thinking about different ways of listening or attending to the experiences of others.

As increasing use has been made of patient stories within service improvement efforts, there has been a growing tendency to think of the patient story as simply another source of data, whereby the story is reduced to its content, which is then analysed, often with a view to finding specific things to fix.

Improving communication and caring relationships also requires a better understanding of what is involved in these often complex processes and this in part entails a closer examination of negative interactions and experiences. *Listening* to stories in this way features in **Only Hearing Negative**, but with a view to looking at a difficult situation from different perspectives and considering empathic interpretations before making connections with and identifying possible improvements within the participant's own practice or care environment.

Equally, **Being Appreciative** encourages attending closely to the story details, but focuses on positive accounts with a view to discovering why some ways of communicating and relating are more enhancing than others and what can be done to replicate positive practices in the local care context.

Challenging Assumptions examines the key parts or touchpoints within stories which reveal that often it is what is not asked, said or heard that is at the heart of breakdowns in communications and relationships.

There are however other ways of listening beyond paying close attention to the story content**. It's the Way I Tell 'Em** turns the focus to aspects of narrative form and structure, which are equally important considerations when listening to and attempting to understand the lived experiences of others. Building on this, **A Sense of Meaning** invites the listener to consider the extent to which the storyteller has been able to make sense of the care experience and find a sense of meaning. The examples illustrate that this can have a profound impact on the way that communications are perceived and relationships develop.

Finally, Arthur Frank introduced the concept of thinking *with* stories, as opposed to the more customary thinking *about* stories in his book, *The Wounded Storyteller (1995).* **Take a Walk in My Shoes** considers this empathic way of listening.

Only Hearing Negative
Beyond the Quick Fix

There is of course rich learning to be gained from considering stories that describe when things go wrong. The improvement culture in healthcare is predicated on a model of problem identification and solution. However, communications and relationships are often highly complex and it is important to avoid the tendency to jump in with quick fix solutions such as communication checklists and bullet points. Whilst these can make certain processes more concrete and expected behaviours more visible, they cannot change the way that we communicate or relate.

> "Attempts to organise ideas about communication only create step-by-step, one-size-fits-all models that sound good, but don't work. They don't adapt well and they are too hard to remember under stress (which is just about all of the time)".
>
> Simmons (2002)

Offering mixed accounts that combine effective and less effective encounters within the same relationship can reinforce the point that the communication process is a shifting one, rather than a once and for all happening. However, people are often so preoccupied with problems that it can result in them only hearing negative, with the positive experiences effectively filtered out.

One approach to working constructively with identified issues is described in *Let's Talk About It: Using Stories to Improve Care for Older People: A Practical Guide* This resource is available for download at:
http://www.crfr.ac.uk/reports/cic%20toolkit.pdf

The guide, developed by the *Connect in Care team*[3], comprises a number of story-based resources and offers a framework for exploring and developing practice from an issue identified in the local care environment. The exercise that follows is adapted from the resource *I'd Never Do That.* This resource takes as its starting point the observation that when we read or hear a story about an incident that has nothing to do with us, we feel much freer to ask questions. We also formulate opinions about why the incident happened and who was responsible and what we would have done. Of course, in these situations we only ever have partial information and on that basis it easy to point the finger of blame or find fixes. Staying with our own original condemnation doesn't help us to learn anything new. The exercise facilitates a shift from a place of judgement to a place of understanding and curiosity and comprises three phases:

- Keep the story at a distance – identify all the questions the story raises
- Bring it closer – find personal connections within the story
- Reflect on one's own environment and practice

[3] Connect in Care Team comprises Dr Heather Wilkinson, Dr Esther Walker, Alexandra McCauley and Alison Forbes. The Connect in Care project, on which the resource is based, was funded by NHS Education for Scotland and NHS Quality Improvement Scotland with support from the Care Commission.

Exercise: I'd Never Do That

Read the following text to the participants**:**

Mary was born with physical disabilities and also has learning difficulties. She lives in her own flat, which has 24 hour care on site. She had lived there without incident for many years before having a nasty fall. As she was badly bruised and shaken, her **carer** decided to get her checked out at A&E. Mary was first seen by a **nurse**, who decided to get a **doctor** to have a look at Mary and she informed the doctor of Mary's situation. The doctor was shocked by Mary's injuries and questioned Mary's ability to live on her own. This upset Mary hugely, particularly as she had to fight very hard to move into her own flat.

This is Mary's story:

"Last year, a doctor told me I shouldn't be living on my own.

My grandmother brought me up and after a while she had a stroke and I had to go away to the Borders. I had no say in the matter. My parish priest and my welfare officer, they put me away in the convent. My priest said you'll maybe not see your family again. It drew you down a bit. I wasn't a child, I was thirty years old. It was a terrible, a terrible time. But I got out when I was 38. I got a place in a group home. There was 10 of us in it and then eventually we got flats of our own, but we still got the 24 hour care and everything. I had to work at it. I had to show I was able. I mean I've done everything.

And then I had a fall and ended up in A&E. I moved into the flat in 1983 and that was my first time there. I had carpet burns on my face and legs and scrapes on my elbows and everything. I was a right mess and I thought it would be best to get it all checked over, but you didn't get it all sweetness and light I'll tell you.

I spoke to the nurse first and she checked me over for everything and she went to get a doctor. And when the doctor came she said "You shouldn't be living on your own. Who agreed that?" Oh, she was right nasty. My carer was with me, but the doctor never spoke to her. Never asked her anything. She just bawled at me. "You shouldn't be on your own". She made me feel I was five years old. That was my first time there and it was a terrible experience. If I did anything like that again, I would want them to treat me with respect"

Mary's story is adapted from *Digital Storytelling in Health and Social Care.*

Steps

1. Individually, record your personal responses to the story.
   How did you feel?
   What does the story make you think about?

2. On your own, consider what draws your attention most in the story?
   Write down the questions that you would you like to ask.

3. Break into groups of 4 (or however many characters feature in your chosen story) and compare the questions that you have identified.
   Organise them into categories.

4. Discuss:
   What similarities and differences do you notice in people's questions?
   How do professional roles influence questions asked?
   What assumptions are made?

5. Write the name of each character on a separate piece of paper and fold.
   Each group member selects a character.

6. Individually, imagine yourself in the shoes of your character and write the story from that perspective. Try to be sympathetic and really explore the possibilities remembering that most people act out of good faith and try to do a good job.

7. The group identifies each character in turn and listens to the story from that perspective.

8. The others in the group then hot seat that character by asking the questions relevant to that character identified earlier. When responding answer using 'I'

9. What did you learn by seeing the story from the different viewpoints?

10. Now consider your own work environment.
    Can you imagine this sort of incident happening in your own work environment, perhaps in a more subtle form?
    What sort of safeguards do you have in place to stop this kind of thing happening?
    How confident are you about these safeguards?
    Where are the weak points?
    What could be done to address these?

Being Appreciative
Learning from Positive Caring Practices

"Change begins with the questions you ask"
Peterson (2000)

Current approaches to improvement tend to focus on the identification of problems and the derivation of solutions. There are however many *good things* happening in care settings. By attending to the details of these good things, we can begin to develop a better appreciation of what works well and why.

Here a number of appreciative stories are shared. The stories address different time spans, from the building of enduring relationships, through single consultations and 'ordinary yet extraordinary' everyday encounters to magical moments in time.

Such experiences, when reflected upon, offer a way of understanding how some ways of communicating and relating are more enhancing than others. Together they illustrate that skilled communication can happen in the smallest of interactions as well as the processes that define the service.

The stories can simply be offered for private reading and reflection, or read aloud and discussed in a group setting.

Questions to consider in each case include:

- How does this make you feel?
- What does it make you think about?
- What draws you attention?
- What particular aspects of communicating and relating does the storyteller value?

Follow-up questions include:

- Can you identify any common themes across the stories?
- Think now about your own care practice - what connections can you make?
- How might you replicate these positive caring practices in your own care
- environment?
- Do people take time to think about what works well and why?
- What would help this to happen more?

Building Relationships
Ruth's Story

I've had COPD for about 15 years and osteoporosis. You get awfully bored with COPD, you get awfully bored with long periods of time when you can't do anything and your breathing's hard and you do get a bit despairing at times.

Last year I got cancer in the middle of the year and so did my sister. Then my grandson had to have a pulmonary valve operation and then my mother died just before Christmas. I had to fly home for the funeral. So when I came back here in January I fell into a trough, no feeling, don't care, no appetite, no nothing. Well the best thing that happened to me was first of all when Claire walked through the door. She arranged for the pharmacist to come and sort out all my drugs with me, but more importantly, you had somebody that you could ask silly questions of and who didn't get annoyed, and actually went and tried to find things out for you. And then the next person through the door was Annie – the door was just cranked wider and wider.

I do have a family, very loving and close, but they're inclined to say no, no, we'll do it. They negate you. Families are wonderful to have, but they're not the 100%. That's what's so wonderful about having somebody who's with but not of. I can say things to Annie and she doesn't go all professional on me. She listens to me. She's also very good to talk at, because you can get your thoughts in order. I can ask her any questions, she liaises with my doctor and with the hospital, and she got me my beloved walker. What a difference that's made to my life; that is just enormous. I used to be very frightened about going out. It was the fear of collapse. I wasn't afraid of collapsing and dying, it was the fear of humiliation. But I'm not frightened with my walker, and I'm really glad that I've got my independence back.

I used to be a lot more than I am now, people forget. There was more to me than this. I think that's where the humiliation comes in. And one of the other things that you can fall into is this ennui of the spirit if you like; it doesn't matter what I look like. It really does. I shouldn't go out in my baggy tracksuit bottoms, I'm sixty-five; this is not dignified. So I've discussed this with Annie and I've decided, now that I'm feeling good again, next time I'm going to go to an expensive hairdresser and get my hair streaked and I'm going to have a make-over.

It's not just the practical things that she does; well in fact that's the least of it. It's the relationship that's very important, it really is. It's having a relationship with that one person that you can talk about all your fears with, no matter how stupid, or your ambitions, and have a laugh, and build a relationship.

Beyond the Magic Wand
Lorraine's Story

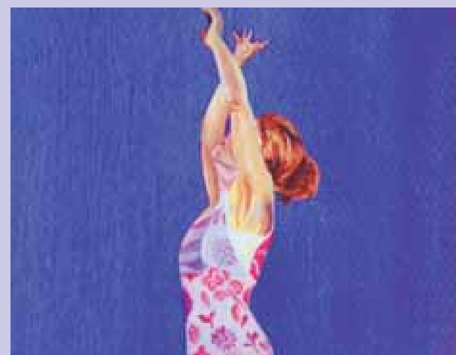
I was working as a development officer when I began to experience feelings that were very alien to myself of self-isolating, being unable to concentrate on the work that was to hand and this all led to me resigning from my job and going back to my parental home. I felt very anxious, as though the fabric of my life was falling apart. I was very fearful and desperate when I entered my GP's surgery, which was my first port of call.

At that point I was looking for that instant cure, that GP's ability to wave that magic wand and make all my symptoms disappear. Although she didn't perform my expected magic, she did play a vital role in allaying my fears and normalised the whole experience by telling me that 60% of her caseload that day was actually mental health problems rather than physical and that just made me feel much more akin to other people and their experiences, that I wasn't this isolated individual who was the only person in the world experiencing symptoms of depression.

Her reassurance and her initial sowing the seeds of hope were just so important at that crucial stage. She gave me time to actively listen and was trying to find the causes rather than just deal with the symptoms. She wanted to know what was going on in my life that had caused me to feel this way and had that genuine interest in finding the source.

She also validated the experience instead of just writing me off as somebody that had something going on in their head, and also crucially said let's wait a while before prescribing medication, you've been through some massive life changes in the last couple of weeks, so let's wait and see if things settle down naturally. So I left the surgery feeling much more grounded, I knew what was going on, but I also felt much more hopeful that a huge disaster wasn't going to befall me.

In retrospect I realise that a good professional looks beyond the surface and the instant cures, and that her intervention was far more meaningful and profound and went way beyond the magic wand.



Always a First
Bill's Story

I took up golf at an early age and it became the second love of my life, the first love being my wife and we've been married a long, special time, and we're now great grandparents. So I'm as happy as Larry when I wake up one morning with a start, falling all over the place and the next thing I knew I was whisked away to hospital.

All the time I was in there, I was totally inert in my right side, and I was just lying there, not knowing just what was going to happen to me. I was very frightened. I was never one for going to the doctors and I kept thinking; what have I done to deserve this? The future seemed awfully bleak and I thought who's going to bother with an old fool like you? Then came the day when these two physios came to see me and one of the girls, I'll never forget her, Jacqueline. She must have seen something in me that told her I was determined to get back on track. She looked me in the eye. And I just knew, in that moment, from her belief and her motivation, that if there was any movement at all, she was going to build on that. And it was a wonderful feeling. Hope. She was a very special girl. And within a week she had me moving my arm a bit.

Then she told me that they were moving me to another hospital and I was very disappointed, as I'd been there with my wife a number of times and it was generally full of elderly people. I thought it might be a place that it was very convenient just to shove all the no-hopers. But Jacqueline told me that she visited there twice a week and I wasn't getting away that easily as we still had a lot of work to do, and I was greatly encouraged.

When I first moved there however, I thought it was awfully depressing. They put me in amongst all these poor souls and I thought what have I come to here? They were shouting and bawling. It would have been very easy to get down, but Jacqueline wouldn't let that happen. She never doubted that I would get better and sure enough after the first week I was getting better and better, and she would say "every day's a first". And right enough, every day after my physio I could feel that I was doing something better. And one day she asked me what sports I played and when I said golf, she told me to ask my wife to bring in a club for me and she'd take me out the back to practice my swing. So the joke is, I spoke to my wife and lo and behold she brought me a putter! What a laugh we had. It was the best medicine.

Since I got home I've been making steady progress. I haven't gone onto the golf course and played golf yet, no way, but I have walked a couple of holes. And it's like Jacqueline said, it's stuck with me:
There's always a first. There's a difference every time you do something.

The Mirror
Karen's Story

Victor, my father-in-law and friend, died in August of this year at the age of 94. He was in hospital for three long months beforehand. The staff were all pretty good, but there was one chap who stood out; a clinical support worker called Dennis. Victor used to call him Dennis the Menace and Dennis would wave a disapproving finger at him and then wink. The pair of them had a great rapport.

At one point, when Victor had been in for several weeks, his hair started to look a bit wild. He had always been so smart and taken such pride in his appearance, and there he was in his saggy pyjamas with his hair sticking out. It made him look eccentric and compounded his infirmity. We asked about a hairdresser. It may have seemed trivial, what with all that was wrong with him, but there was an advert on the notice board. However, nothing materialised and on the one occasion that the hairdresser did come in, Victor was having a bath. He was dreadfully disappointed, but Dennis piped up, “we can’t have this, I’ll do it for you if you like.” He told us that that he’d had lots of practice, as he used to cut his father’s hair. And then he proceeded to cut Victor’s hair. And he took such care. It was one of the most special acts that I’ve had the privilege to witness; this gentleness’ this level of care, this total affirmation of worth. When he finished, Victor thanked him and Dennis touched his hand and said ‘my pleasure, Victor’. And you knew that he meant it. Then Dennis went to look for a mirror and I thought to myself, he doesn’t need a mirror. When he looks at you, he sees a positive image of himself. You’re the only mirror that he needs. That was Victor’s last hair cut. It’s a magical memory that I replay over and over in my mind.

Appreciating Local Caring Practices

Within any given care context there will be similar stories that articulate the special and often hidden acts that are valued by patients and their families.

Take time to gather, share and discuss these stories with staff.

On reading each story, questions to consider include:

- How does this make you feel?
- Is this something that you value?
- What strengths do *you* have that enables this to happen?
- What strengths do we have as a team that enables this to happen?
- Is this something we would like to happen more of the time?
- What would it take to enable this to happen?

To learn more about ‘*Appreciative Inquiry’* readers are encouraged to access: *Appreciating and developing compassionate care in the acute hospital setting for older people.* Dewar, B and Mackay, R (2010) International Journal of Older People Nursing.

Experimenting with Drama Tools and Creative Methods

The role of story in increasing our awareness of how patients, carers and care professionals actually experience their everyday interactions is now firmly recognised. However, where a story is locally owned, it can be difficult for staff to ask questions or to reflect openly on the issues, or indeed the positive practices, identified within the narrative and the process requires careful facilitation. Shifting a story to an external stage can provide a safer environment for discussion, but by detaching stories in this way, we are reduced to partial information and this simplification can make solutions seem easy, compounding the tendency to rush to 'find things to fix'.

Increasingly, use is being made of drama techniques and creative methodologies to address these limitations. One such example was a workshop entitled *Being Appreciative – the Heart of Compassionate Care,* which was run by Belinda Dewar from the Leadership in Compassionate Care programme and took place during the Inaugural International Conference in Compassionate Care, hosted by Edinburgh Napier University in June 2010.

Workshop participants were invited to step inside a storyline that could be encountered in any care setting. Specifically, the interactive drama process encouraged group exploration of a familiar scenario involving three characters – an, elderly male inpatient, his concerned daughter and the nurse in charge of the gentleman's care. While the initial scene was scripted, all subsequent dialogue was directed by the workshop participants, who were first invited to reflect on the story in small groups to identify what they would like to understand better, what aspects of the interaction they thought worked well and what worked less well.

Many participants very quickly formulated opinions about what had happened and what they would have done in the situation. Rather than inviting the characters to ask questions that would enhance understanding from different perspectives as directed, there was a tendency to jump in with solutions. Through skilful facilitation, the participants were gently moved along from this starting position, to recognising the need to take time to uncover initially hidden aspects of behaviours and relationships. Having gained these deeper insights, participants were more able to appreciate the motivations and efforts of each character and ultimately to work with the cast to reach a conclusion that took everyone by surprise.

In a short space of time, this workshop illustrated the importance of an ability to empathise with the experiences of patients, carers and staff, and of giving and receiving feedback in a way that is both valuing and respectful. By inviting participants to step inside the story, it brought some of the assumptions and misperceptions that are embedded in everyday care encounters into focus in a place where they could be dealt with safely and constructively.

The scenario was not only authentic, but was also well known to the cast. Unlike other drama techniques that require participant role play and are therefore dependent upon each participant's ability 'to get into character', the cast members were able to draw upon this understanding in response to participant inputs, enhancing credibility and emotional impact.

Challenging Assumptions
The Eighth Deadly Sin

An examination of the key moments or touch points within stories can reveal that often it is what is *not* asked, said or heard that is at the heart of breakdowns in communications and relationships.

Here a number of story extracts are shared to bring some of the assumptions and misperceptions that are embedded in everyday care encounters into focus. The extracts address assumptions about what patients and their supporters will want, what they are thinking or feeling and the issues behind their emotions, together with assumptions about what they know, what they will ask and how they will behave.

Such experiences, when reflected upon, offer an opportunity to question our own attitudes and assumptions and to consider how these can be challenged as part of routine care practices.

Each of the following scenarios can simply be offered for private reading and reflection, or read aloud and discussed in a group setting.

Questions to be asked in each case include:

- How does this make you feel?
- What does it make you think about?
- Can you understand how these assumptions were made?
- What sorts of measures would have prevented them?

Think now about your own care environment and care practice:

- What safeguards exist to prevent assumptions like this from being made?
- How confident are you about these safeguards?
- Have similar issues arisen – perhaps more subtly?
- What can we do differently?
- What sort of discussions should take place within the care environment to challenge our assumptions?

Scenario 1

Patients may or may not want to do something that we think they will – they may not want what 'I' would want, or what 'I' think they would want:

Whisked Off to Bingo
"When I first moved in here, the staff were concerned about me. I think they thought I was terribly shy. It had just been me and Robert for years and then when he died I was on my own for a long time. I wasn't a good mixer. I never have been. But I was quite content in my own company. Then one day one of the staff came along to my room and whisked me off to Bingo. I've never played Bingo in my life and I was just not interested and I said so. The way I was brought up, well it was against my lifestyle. I considered it betting you see. I really didn't want to go, but she just said 'oh you don't know what you're missing - you'll enjoy it when you get there". I told her that I knew that she was trying to bring me out of myself, but I really did not want to go. But she just ignored me and wheeled me along. I hated every minute and felt quite wretched".

Source: Digital Storytelling in Health & Social Care

Scenario 2

When we make assumptions about what someone will want to do, this may be based on other assumptions about what that person is thinking or feeling:

Moving to the Side Room
"One of the staff asked me the other day if I wanted to move into a side room. I was quite surprised to be offered this. One of the ladies opposite me has dementia and she calls out at night a lot and goes into other people's lockers and takes things. I don't mind though. I like to be in her company. I have a good friend at home who has dementia and I enjoy spending time with her. It doesn't bother me. I don't want to go into the side room. I feel at ease with Janet".

Source: Leadership in Compassionate Care Programme
Edinburgh Napier University & NHS Lothian

Scenario 3

When people get upset or emotional, assumptions can again be made as to the source of this emotion:

But It Isn't the Disruption that Bothers Me
"I can get quite upset at night time. There are quite a few confused patients on the ward, one or two wanderers who try to get up, but they're not fully mobile. It's just unfortunate. The nurses keep apologising for the disruption. But it isn't the disruption that bothers me – I was a nurse for 32 years myself, mostly working in care of the elderly, and I think it's more the fact that I can't get up and help that upsets me. It's instinctive and I feel powerless to do anything. I now know that part of me's gone and it's terribly sad".

Source: Digital Storytelling in Health & Social Care

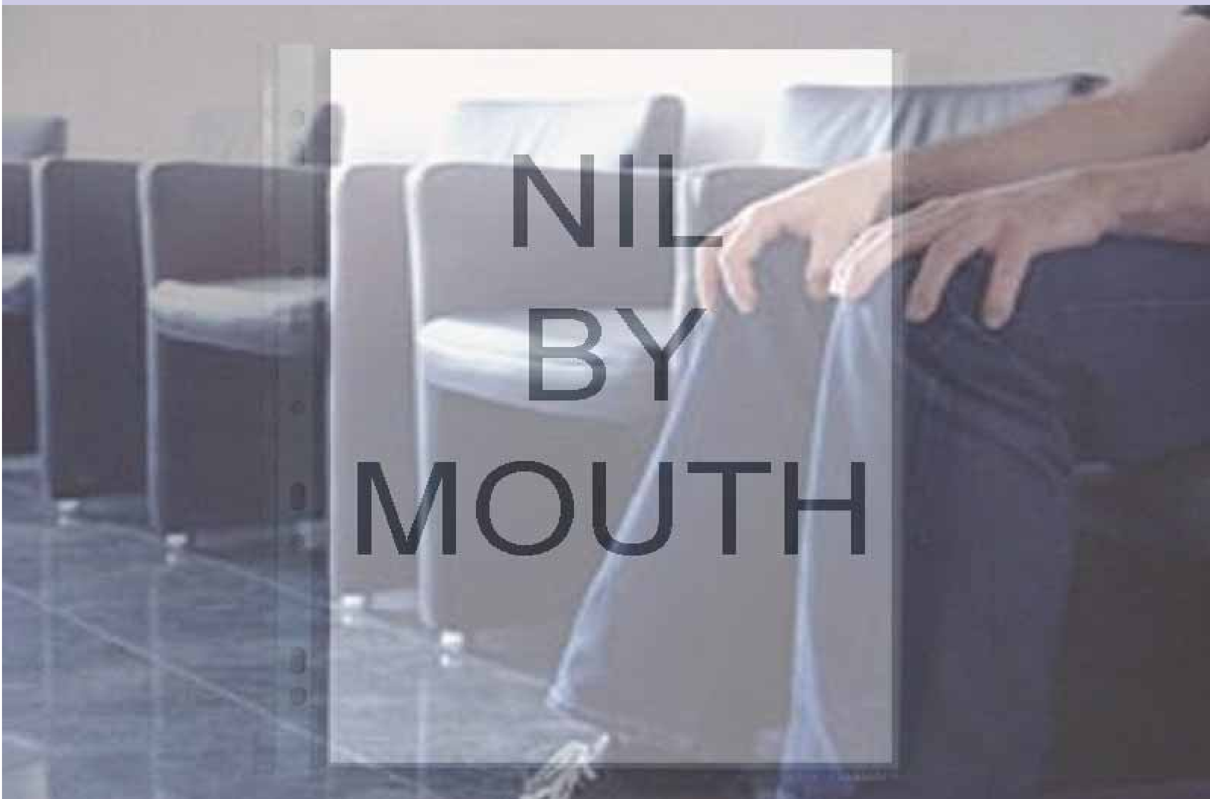
Chochinov (2007) suggests that the following questions should be asked as part of our reflection on the care of each and every patient:

- How would I be feeling in this patient's situation?
- What is leading me to draw those conclusions?
- Have I checked whether my assumptions are correct?
- Am I aware how my attitude towards the patient could be affecting him or her?
- Could my attitude be based on something to do with my own anxieties and fears?

Scenario 4

The rules and routines of the care environment can be a mystery to patients and their supporters and people may be afraid to ask questions:

A Glass of Cold Milk Please
"My dad wanted another glass of milk. It was all he was taking and the doctor had said he could have as much as he liked. But it's not like a café, and there had also been a bit of a set to with the speech and language therapist about his delayed swallow, and not all of the staff were happy with the decision to allow him to drink. But I set off across the ward with his drinking cup. I could see the staff were all extremely busy and there was no one at the station. I knew where the fridge was and thought about filling it up myself, but I wasn't sure what the rules would be, with all the various hygiene restrictions. I'm a 50 year old sales director with a reputation for taking no prisoners, but at that moment I felt like a school boy. I didn't want to disappoint my dad, who was nearing the end of his life, but I was too frightened to stop someone and say 'a glass of cold milk please'. It was laughable".



Scenario 5

At times, relatives and friends may feel that staff cannot be approached, especially about things that affect them, rather than the patient:

The Missing Chair

"We had been given a chair for me. I have bad arthritis and it was easier for me in the higher chair just to sit with my husband comfortably. On one occasion, somebody must have come into the room and removed it. I was quite upset, but it's difficult – there were possibly lots of rules and regulations that we're not necessarily aware of and you're never sure if you're overstepping the mark. We did not feel able to say anything as we are all well aware of the constraints within the health service".

Source: Leadership in Compassionate Care Programme
Edinburgh Napier University and NHS Lothian

In the case of the last two scenarios, additional questions include:

- What can we do to demystify the rules and routines of our service?
- What can we do to encourage relatives and other visitors to ask questions?
- What can we do to encourage support families and friends to share their thoughts and feelings?
- What support do we need to make this possible?

It's the Way I Tell 'Em
Aspects of Narrative

The previous sections have considered the examination of story content in order to identify and better understand particular aspects of the processes of communicating and relating, both positive and negative. In addition however, effective communication and relationships in the care setting have at their heart an understanding of individual patients and their families and the things that really matter to them. Gaining this understanding requires a special way of listening, not only to the details of what they say, but also by paying attention to how the story is constructed and told.

The following use of story aims to increase awareness of the learning to be gained from attending to aspects of narrative – the form or structure of a story and the way it unfolds, rather than focusing solely on the story content. All are important aspects in listening in order to understand the lived experience of the teller.

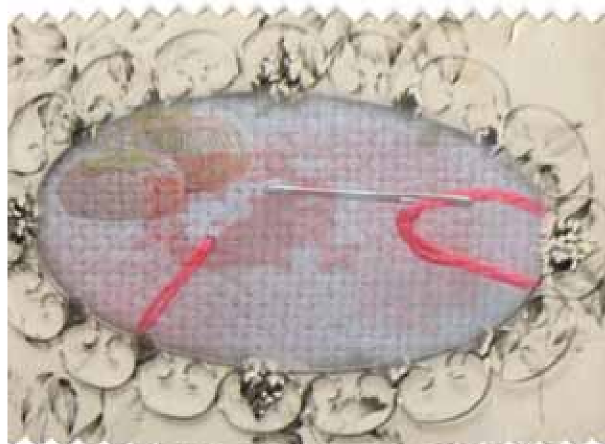
By way of example, the exercise makes use of two digital carer stories available from the Care Story Library: www.carestories.co.uk[i]

Black and White
Christeen's Story

Christeen fulfils multiple caring roles – looking after her husband, mother and also her father at the end of his life. Her story describes the way in which a carefully conducted carer's assessment enabled her to see exactly what her life had been reduced to. This in turn helped Christeen to take stock of her situation and begin to accept offers of support from others. Although told unscripted, this is a 'practised' story that Christeen had told many times before.

A Stitch in Time
Catherine's Story

Catherine too fulfils multiple caring roles, looking after her thirty-five year old daughter who has severe epilepsy, lymphodema and learning difficulties, and more recently her husband, who returned home against all the odds after a massive stroke. Her daughter, who is very reluctant to leave Catherine, was present during the recording and frequently interjects. The story was told spontaneously and conversationally, with a degree of apprehension.



Exercise: Form versus Content

Invite participants to listen carefully to the story and to consider attending to aspects of narrative rather than focusing solely on the content, such as:

- How the story is presented
- The development of plot, if any
- The different characters and the emphasis they receive
- The emotions expressed
- The degree of enthusiasm or coherence in recounting the story
- Does the storyteller have difficulty in finding a story?
- Does the storyteller forget parts or repeat them?
- What seems to be the effect of telling the story on the storyteller?

Coles R. (1989)

Play Christeen's story

Invite comments (and facilitate discussion) about each of the above aspects and then consider the following:

- What conclusions can you draw from the way the story is told?
- Does the way the story is told add to or detract from the impact on the listener?

Play Catherine's story

Invite comments (and facilitate discussion) about the following:

- What conclusions can you draw from the way the second story is told?
- Does the way this story is told add to or detract from the impact on the listener?

- What are the main differences between the two ways of telling?

- What are the implications, if any, for your own practice?

A Sense of Meaning
Reflecting on Experience

"Stories are products of reflection but we do not usually hold on to them long enough to make them objects of reflection in their own right."

Schon (1983)

A further educational use of patient stories considers listening to a story with a view to discerning how the teller is making sense of the experience and the extent to which a sense of meaning or purpose has been found. This application builds upon **It's the Way I Tell 'Em** and serves the following purposes:

First, if we are to ask people about their experiences in personalised and sensitive ways, this should be based on at least some appreciation of how the individual is making sense of the experience. (Allan, 2000). The way communications and relationships are experienced in care settings can be highly unpredictable and the care practitioner has to respond to frequent changes and crises. To do so requires an understanding of the particular way that patients and families respond to events in their life in order to work in a real partnership.

Second, if we are to use patient stories as a learning tool (or increasingly as a powerful communication vehicle) here again the listener should be able to give some consideration as to how people who use care services make sense of their experience of doing so, and the impact of this on their communications and relationships within the care setting.

The following group exercise can be used to explore this further. It makes use of two digital stories, featured in the collection '*Whose Care, Whose Lives'* and are available from www.carestories.co.uk[i]. However, any pair of similarly contrasting stories, visual, audio, or written, could be used.

The example features the stories of two ladies who are being cared for in the same continuing care hospital ward. Both were admitted around the same time. For one living in the hospital is dominated by a sense of loss of the home she loves and her independence; for the other the senses of continuity and familiarity are much more prominent.

Exercise: Making Sense of Experience

Focusing
Invite the participants to listen to the story (and if building on the previous exercise to think about the aspects of narrative as well as the content).

Play Agnes's Story: "Why Not?"

Reflection and Discussion
Facilitate group discussion around the following questions***:***

- How did you feel listening to the story?
- What did you notice?
- What do you think / feel about Agnes and her situation?
- What do you think / feel about Agnes's care?
- What conclusions have you reached about the communication and relationships with the care staff?
- What questions would you like to ask?

Refocusing
Inform participants that May and Agnes were admitted to the same 4 bedded ward around the same time and that both receive continuing care.

Invite participants to listen to May's story

Play May's Story: "A Very Familiar Place"

Reflection and Discussion
Facilitate group discussion around the following questions***:***

- How did you feel listening to ***this*** story?
- What did you notice?
- What do you think / feel about May and her situation?
- What do you think / feel about May's care?
- What conclusions have you reached about May's communication and relationships with the care staff?
- Has hearing this story changed the way you feel about Agnes, or her situation? Should it?
- What if the two stories had been shown in reverse order?
- Does this highlight any assumptions made previously?
- What does this tell you about the use of patient stories as an educational tool?
- What does this tell you about the use of patient stories as a communication tool?

Individually, consider any connections between these accounts and your own experiences of care giving.

What learning might you want to take back into the workplace?

Take a Walk in My Shoes
Insight into the Lived Experience of Others

Patient stories can be used to help to develop another special way of listening, which entails being drawn into the unique reality of that individual to hear the core essence of their story. This can be likened to talking a walk in someone else's shoes or thinking *with* stories.

> "You have to learn to think with stories. Not think about stories, which would be the usual phrase, but think with them. To think about a story is to reduce it to its content and then analyse that content. Thinking with stories takes the story as already complete; there is no going beyond it. To think with a story is to experience it affecting one's own life and find in that effect a certain truth of one's life".
>
> Frank (1995)

While the above quote refers to richly detailed narratives sharing the lived experiences of illness, the same listening principles can equally be applied to shorter accounts.

The following selection of short stories, poems and images is offered by way of example. Readers are invited to choose the story that they most identify with and then read this again, this time imagining themselves in the shoes of the teller.

A Very Special Child
Mo's Story

My first grandchild was born three months after my stroke. I was so looking forward to the arrival of this child I'd waited so long for. When Chloe arrived, the euphoria I first felt was replaced by heartache when I realised that not only could I not cuddle her, but I could not feed her, change or bath her, or do any of the things that grans do, and was so jealous of those who could.

Chloe was around six months old when I had enough movement in my right hand and arm that I could hold her for the first time and it was this that spurred me on to get more movement and continue to make progress.

Now we plant seeds together, bake together and make her favourite macaroni and cheese together. In fact, she refers to my right hand as 'gran's shoogely hand'. She really is a very special child.

Another Morning Gone
Moira's Story

Imagine every morning feeling jet lagged
Flu-like
As if you'd gone several nights
Without sleep

Imagine seven years
Of being unable to see a morning
Never seeing the morning sun

Imagine nausea
And being totally unable to focus
Or stay awake
Without falling into collapse
On the floor

Imagine M.E.

They're Not My Friends
Beatrice's Story

Having a child with a life limiting condition is hard in many ways. One of the things I found difficult during the first three years, because our life was reduced to just looking after our daughter, basically we didn't - and still don't - have a social life any more. Which means that the carers who come into your house, to you, become friends. But of course, they're not; they're paid to provide a service. But that's not how you think of them. You think of them as friends, because that's the only way you can cope with so many people coming into your house, which on one level is quite an intrusion on your privacy. And the way, especially my son and I dealt with it, because we were the ones who were home, was to think they were friends, who happened to look after our daughter. But then these friends would suddenly up and leave because they had a new job, or they'd been promoted or they went to work somewhere else. And they never came back. And it meant for my son in particular that he went from treating them like friends to treating them like servants almost. He was a little boy then and he said "mum, if they were my friends they would come back and visit me again" but they never did. "They're just going to leave again anyway, so if I start liking them, then it'll hurt me even more if they go again". And that was quite hard to explain to a four year old kid, why these special people would suddenly not be special people in his life any more.

After reading the story again, consider the following questions:

- How do you feel reading this?
- In what way did this particular story affect you?
- What connections did you make with the story?
- What aspects of patients’ and carers lives should be known to provide the best possible care?
- What might be the consequences of not knowing?
- What are the implications for practice in your care setting?

> “Treating a patient’s severe arthritis and not knowing his core identity as a musician, providing care to a woman with metastatic breast cancer and not knowing that she is the sole carer of two young children, attempting to support a dying patient and not knowing that he or she is devoutly religious - each of these scenarios is equivalent to attempting to operate in the dark”
>
> Chochinov (2007)

Catching a Story Without Falling Down
Exploring Diversity and Complexity

Anne Fadiman's 1997 text '*The Spirit Catches You and You Fall Down'* is a cautionary tale of culturally ineffective care. A gripping and acclaimed story, its use in education has however been criticised as presenting a one dimensional, simplistic view of culture that has the capacity to "catch the reader and make the reader fall down", unable to move beyond its extreme and obvious lessons to recognise that most cultural clashes in the care setting are far more subtle that those depicted in the text. [Taylor, 2003]

This example, although somewhat unusual and dramatic, nevertheless touches upon a common concern associated with the use of the single story as an educational tool: how to mitigate against the risk that the story might be interpreted too literally or simplistically - as a text – an account of what to do or say in a similar situation, with someone with this particular condition or set of circumstances, and that the subtlety and ambiguity that characterises communicating and relating in a caring context will be masked.

Much depends upon the way any given story is presented, the questions posed and the subsequent dialogue. When thinking about applying the key story messages in a particular care setting, it is crucial that practitioners are supported to gather and work with other forms of evidence and to relate the story to the local care context and culture.

Twin Sets and Pearls

One approach that can be used to build up a picture of the diversity and complexity of encounters and relationships in caring situations is to provide opportunities to listen to a range of stories.

An example is the use of paired stories or *twin sets*, such as those featured in *A Sense of Meaning***.** While this story set was used to illustrate deliberately marked contrasts in experience, paired stories can also be used to provide different perspectives on the same situation, such as the person receiving care and the care giver, or to introduce subtle variations.

Another approach is to develop a collection of stories. Each story is a valuable learning resource in its own right, but when put together the stories are transformed into something quite different and complete, much like a string of *pearls*. Those committed to using patient stories as an educational resource may find it helpful to make room for a few twin sets and pearls in their story closet.

Using Stories to Make a Point

Story as a Communication Tool

The previous sections have considered the use of patient stories as an educational resource to help improve communications and relationships. To conclude, this section turns explicitly to consider the role of story itself as a powerful communication tool. The use of story as a tool of inspiration, influence and persuasion is well documented. Story features strongly in all major religions and more recently has seen an abundance of books on 'organisational storytelling' hit the shelves.

In the course of teaching others about communication and relationships, story can be used to good effect to make a specific point. People learn from story. People remember stories.

If you have a specific point that you would like story to help you to make, you have three basic choices:

- Tell a story that is already known to you
- Identify an existing story that illustrates your point
- Invite people to tell you a story within the area of interest

Story Finding

There is no shortage of documented patient stories, either written or increasingly in digital form. The latter can be accessed from websites such as the award winning www.patientvoices.org.uk and www.healthtalkonline.org

One question often raised is whether a story serving to convey a specific point should be taken from the local care context or elsewhere. Both offer certain advantages and disadvantages, but this question needs to be situated within a broader consideration, namely 'what are the attributes of story that will determine its impact on the listener', as discussed opposite.

The other means of finding a story is to invite people to share their experiences within the area of focus. Here, Simmons offers the following advice:

> "If you can't find a story that makes your outcome feel important to others, are you sure your outcome is important?"
>
> Simmons (2002)

Inviting someone to tell their story is not the same as eliciting a report. The teller must be given control over what they say and what they omit. This approach to story gathering is quite different to some methods used to collect patient stories for the purpose of service improvement, which are typically elicited through the asking of quite specific and often service or practitioner led questions.

If the story is gathered through an 'interview' process, the role of the listener is primarily that – to listen - and to encourage the teller to take responsibility for the meaning of their talk (Chase, 2003), occasionally picking up on cues.

An alternative approach is to invite the teller to write or audio record their story in their own time. Here it *may* be helpful to provide some guidance as to what makes a good ‘teaching’ story in general terms. This however is quite different to making suggestions about the story content.

The process of finding a story that will help you to make a point can be likened to finding a painting: You may already have a particular piece of art in mind, you may go to a gallery a find a painting that ‘speaks to you’, or you could invite an artist to paint something for you, but again Simmons advises:

> “An outcome focus in storytelling is like asking an artist to paint a picture to match your couch. It can be done, but it’s not art”.
>
> Simmons (2002)

It is also rather self-serving and potentially manipulative.

Story Crafting

What makes a good ‘teaching’ story?

Essentially, a good teaching story is one has an impact on the listener and is remembered. There is a craft to telling a good ‘teaching’ story, but it is best not to get too hung up on rules and story elements and instead trust the storytelling process.

The intention is always to connect with rather than impress the listener. This encourages telling a story in the first person, openly and honestly, and from the heart.

Attributes of a good *‘teaching’* story include:

- ‘**Point**’ – the story delivers a clear message
- **Authenticity** – the story recalls a real experience rather than a contrived scenario
- **Credibility** – the story is believable and rings true
- **Emotional content** – the story touches hearts as well as minds
- **Context** – the story situates the teller in time, place and circumstances
- **Relevance** – the story is of personal and immediate interest to the listener
- **Brevity** – short stories can hold the listener’s attention unbroken

Of course, it is important to appreciate that **not everyone likes stories!** There is no one best way to get a point across. While many people enjoy and learn from stories, others will prefer more formal presentations.

Irrespective of the listener’s preference, it’s also important not to overlook the dark side of story, which could result in its use, misuse or abuse to promote a specific agenda. Be prepared to back up your point with facts and figures using other forms of evidence.

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Featured Images

Listed in order of appearance:

Dandelion Seeding: Image by Dreamstime
From the Digital Story: *Differently the Same*
Challenging Assumptions: Living with Dementia Collection

Hope Stone: Image by Lorraine Nicholson
From the Digital Story: *Beyond the Magic Wand*
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[Personal Collection]

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All referenced digital stories were created through the *Digital Storytelling in Health and Social Care* project, which was taken forward in association with the Scottish Government's Joint Improvement Team www.jitscotland.org.uk.
This project concluded in September 2009.

The digital stories are available for download from the Care Story Library www.carestories.co.uk[i]

[(i)] At the time of printing, the Care Story Library was in the final stages of development. As an interim measure, a small selection of stories is available via a holding page. Permission has been secured to make these stories available in the public domain.

Care Story Library registration will be available in December 2010.

Better Together

NHS Education for Scotland

This resource was developed by Karen Barrie, Better Together: Scotland's Patient Experience Programme, Scottish Government

The resource was created to support the NHS Education Scotland focus on improving communications and human relationships, with an emphasis on integration with everyday care practice.

For more information please contact: **karen.barrie@nhs.net**