

Telling Stories: Understanding Real Life Genetics

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This Wellcome Trust-funded, multi-media web-based education resource uses real-life stories from the public and professionals to promote knowledge and understanding of genetics. It is being developed for non-genetic healthcare professionals to encourage understanding of genetics, and its impact on peoples' lives. Target users include nurses, midwives and health visitors (both educators and practitioners), any other interested health professionals and patients and the public.

The genetics White Paper 'Our Inheritance, Our Future' (Department of Health 2003) emphasises the need to develop and include genetics in everyday health professional practice and education. This involves improving professional understanding of genetics, including its relevance to practice and impact on the lives of individuals and families with, or at risk of a genetic condition. Nurse lecturers often lack genetics experience so have few real stories to tell, and may not recognise fully the learning opportunities within a story. Lecturers may support genetics but lack confidence in teaching nurses about it.

Following ethics approval, nearly 90 stories have been collected in text and video formats from patients, carers and practitioners and collated into themes based on the seven genetics competences of the education framework developed previously by the group.

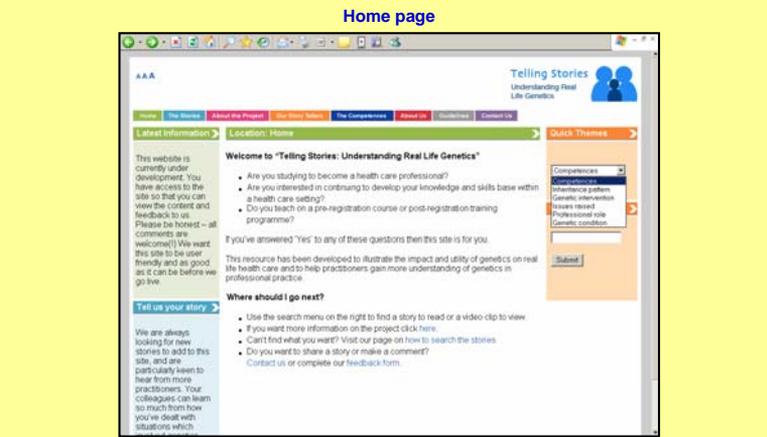
Stories are useful additions to formal learning because they are understandable, memorable, stimulate critical thinking, promote active listening and discussion about complex situations and link theory and practice. Life isn't like a textbook! Stories are sought through a number of ways, including support groups, newsletters and conferences. Informed consent is gained, then stories are collected by written submissions or video-taped interviews.

Each story is linked to one or more of the seven genetics competence statements. The stories are available as text and video clips, together with additional explanations and glossary. They are searchable, and feature pointers for reflection and discussion, suggested learning activities linked to the story and links to support groups and other resources.

The website will provide a comprehensive teaching and learning 'package' based on the competence framework, which, although initially developed for nurses, midwives and health visitors, is of value across the healthcare professions, and use by other groups is encouraged.

Of the 87 stories collected so far, 28 are video-recorded and 59 are text submissions, with seven from health professionals, 39 from carers/partners/family and 41 from those with 'lived experience'

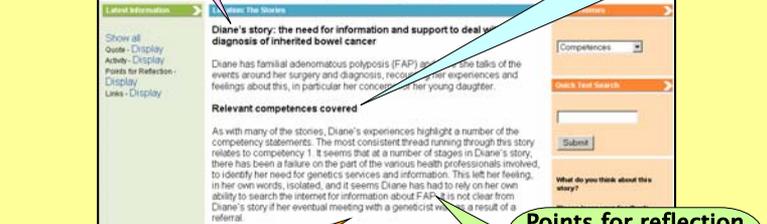
This resource is hosted by the NHS National Genetics Education and Development Centre.
<http://www.geneticseducation.nhs.uk/tellingstories>



Activities
 1. How would you represent Diane's family tree, using the standard pedigree symbols?

Screenshot with story annotations

Relevance to this competence
 The most consistent thread running through this story relates to competency 1. It seems that at a number of stages....

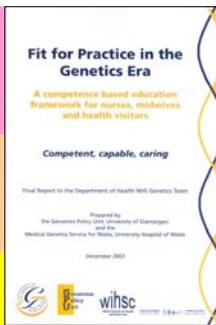


Quotes to reflect on
 "It is difficult to put into words just how isolated I felt during that time."

Points for reflection
 1. If you were a children's nurse, how do you think you would have responded if Diane had approached you and asked for your help in getting her young daughter tested for FAP?

The main reason for doing this

"Well I think the main thing is if you are listening with an open mind and you just take time to think about it and just try and read up on it or get some sort of foresight on it you know, that's all I want. As long as you get some sort of educational understanding about it that would please me." 13



All nurses, midwives and health visitors, at the point of registration, should be able to:

Competence 1 Identify clients who might benefit from genetic services and information.

"The one thing which still makes me wonder is that six years earlier my husband had a colonoscopy and had several polyps removed and sent for biopsy and he was told he didn't need any follow-up treatment or further investigation. I can't understand why they didn't link it with FAP then." 10

Competence 2 Appreciate the importance of sensitivity in tailoring genetic information and services to clients' culture, knowledge and language level.

"One thing that was important was the day I was diagnosed my mother asked the doctor if there was anything I should not be told – at least at that time. I was sent from the room while my mother was told the full extent of the condition including the fact that I am infertile ... I have never really ever felt fully able to trust my parents ... to this day." 22

Competence 3 Uphold the rights of all clients to informed decision making and voluntary action.

"The diagnosis meant our other two children were at 50% risk. They were 6 and 4 at the time. I was desperate to know if they were free of the gene. We saw a geneticist who had a genetic nurse with her. To their eternal credit they withstood our pleas. How they managed that I don't know. They said they were the children's champions. The children were too young to speak up for themselves. Their job was to preserve the children's genetic status for them so they could make their own choices about testing when they were older. If I ever meet them again I will kiss them and thank them." 48

Competence 4 Demonstrate a knowledge and understanding of the role of genetic and other factors in maintaining health and in the manifestation, modification and prevention of disease expression, to underpin effective practice.

"It's hard to get through to somebody who doesn't know, who hasn't lived with it or hasn't lived with somebody who has got it. A lot of staff when you go to these different wards, they don't believe you. They just don't believe you. They say, well you can't be in that much pain. They actually think you want to be there. I mean, I don't want to go into hospital. Nobody wants to go into hospital. So I'm not going to make up stories that I am in that pain just to get some drugs. It don't make sense. I would rather somebody explain to that staff member who has no knowledge of it to explain to them this is what's going on, rather than me getting agitated and angry, and explain it to that person." 13

Competence 5 Demonstrate a knowledge and understanding of the utility and limitations of genetic testing and information.

"The bomb was dropped with great compassion but even so, the shock was enormous, verging on physical, in its effects." 49

Competence 6 Recognise the limitations of one's own genetics expertise.

"Don't be afraid to say 'I don't know' instead of guessing and being wrong and losing parents' trust." 38

Competence 7 Obtain and communicate credible, current information about genetics, for self, clients and colleagues.

"It was very fortunate for us that we had a brilliant health visitor who gave us all the support she could offer. She helped us find out all that she could, even though she knew as little as we did. She spent much of her own time doing research on the internet about the condition and where to get some special growth charts for my son to record his progress." 33

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