

'Living with Genetic Conditions': An educational tool to promote knowledge and understanding of rare diseases

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Introduction: The power of personal stories is widely recognised, being increasingly used in health to capture the patient voice and promote patient-centred care^{1,2}. Established in 2008, *Living with Genetic Conditions* is an educational session to inform others about genetic conditions, which are often rare, and promote understanding of the impact they have on everyday lives and on healthcare practice.

Approach: Each educational session focuses on a particular condition, e.g. cystic fibrosis, tuberous sclerosis complex, haemophilia, Huntington's Disease. Originally developed as a resource for schools, the session can be accommodated within a lesson and run in association with the biology curriculum or personal, social and health education teaching. The format of the sessions is as follows:



Talk from a genetic counsellor:

- Clinical information
- Genetic information
- Practice and management



Personal narrative:

- Can be from an individual with the condition, family member or carer
- Describes the impact on everyday life



Question and answer session:

- An opportunity to gain further insight into living with a particular condition and explore challenges faced by the rare disease community

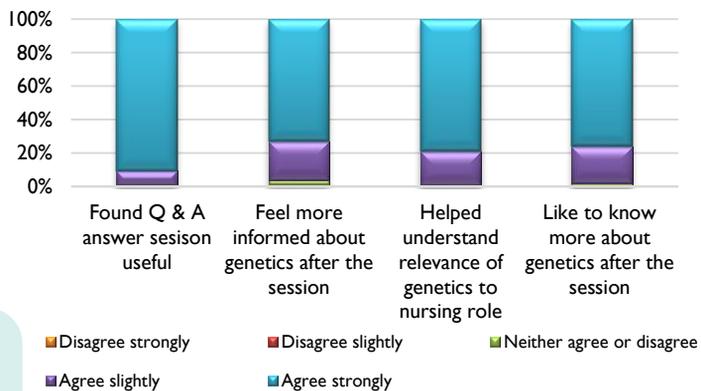
Findings: Evaluation of the sessions has shown they are received extremely positively, promoting interest, engagement and questions from all audiences.

Examples of twitter feedback on the sessions



Figure 1 shows evaluation data from an undergraduate nursing students cohort in 2015 (n=107); 99.1% agreed the Q & A session was useful; 95.8% agreed they felt more informed about genetics after the session; 99% said it helped them understand the relevance of genetics to nursing; 97.9% wanted to know more about genetics after the session.

Fig 1. Undergraduate nursing students evaluation (n=107)



Experiences of taking part

"It was clear that the students were really engaged by the thoughtful questions they asked. I found the talk from the patient perspective really valuable and inspiring which helped with my own professional development."

Trainee genetic counsellor

"Through sharing our personal experiences of family life and living with a rare genetic disorder, I have been empowered.....sharing my experiences with students and others who will provide care for families like mine is so important; knowledge is key to improve future outcomes for my son and others who live with a genetic disorder"

Speaker, Living with Genetic Conditions

"Very informative and great to be given the opportunity to ask questions to find out more about CF from a patient's perspective"

Nursing student

"A fantastic and rare opportunity for trainees to really hear about and understand the experiences of families. This leads to better care for these families as trainees provide better support to patients and know how to link in with genetic services"

Genetic counsellor

Conclusion: As well as raising awareness, *Living with Genetic Conditions* provides an important outlet for the voices of those affected by rare diseases. As a result of its success, it has now been expanded to undergraduate students, university summer school students and community groups (e.g. The University of the Third Age). This year it is also being run as a series of new events to promote understanding of rare diseases amongst the public.